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**AN EXPLORATION OF FAMILIES' EXPERIENCES IN
MANAGING HYPERTENSION CONTROL IN
DENPASAR, INDONESIA: A QUALITATIVE STUDY**

NI KOMANG ARI SAWITRI

**Thesis submitted in fulfilment of the requirements
of the degree of Doctor of Philosophy**

**THE UNIVERSITY OF EDINBURGH
2019**

Declaration

This is to certify that the work contained within this thesis has been composed by me and is entirely my own work. No part of this thesis has been submitted for any other degree or professional qualification.

A handwritten signature in black ink, appearing to read 'Ni Komang Ari Sawitri'.

Ni Komang Ari Sawitri

Abstract

Background: Hypertension is understood to be a lifestyle disease and is most commonly experienced in adulthood. The prevalence of hypertension in Indonesia among individuals aged ≥ 18 years old in 2018 was 34.1% (Ministry of Health Republic of Indonesia, 2018). In 2012 hypertension was a major cause of hospitalisation in Indonesia, with cardiovascular diseases and stroke being the main reasons for deaths in hospital (Centre for Data and Information, 2012). The current hypertension management model in Indonesia follows the Ministry of Health, Republic Of Indonesia's guideline and is focused on the individual patient. The individual approach to hypertension control may not be the most appropriate if families have a significant influence on daily practices and all matters of particular relevance to those members who are affected by hypertension (Tull et al., 2013; Ribeiro et al., 2011). Family life in Indonesia reflects an inter-generational family structure, with families living together in one house. Given the importance of inter-generational families and family life, daily hypertension management often goes beyond the patient and includes other family members such as the marital partner, children (adult and dependent) or grandchildren. It is this complexity and interaction within and between family members that requires an in-depth exploration into how patients and their families deal with the day-to-day management of hypertension and thus this is the unique contribution of this study.

Aim: The aim of this study is to understand families' experiences in managing hypertension control on a daily basis in Denpasar.

Methodology: This focused ethnographic study draws on General system theory, the agency-structure concepts, and Protection motivation theory. Semi-structured interviews (individual, dyadic, and group), and participant observations were conducted with 11 families (44 individuals participants) in Denpasar. The individual interviews were conducted with 13 participants, dyadic interviews with 9 couples, and group interviews with three families. The participant observations were carried out between February – July 2016 at the families' premises, clinics, and parks in Denpasar. The data was analysed using Coffey and Atkinson's (1996) approach to analysing qualitative data; included in the process are: coding, generalising and theorising.

Findings: The most important insight from this study is that hypertension is not controlled by the individual patient alone, but that there are dynamic processes within families that influence daily hypertension control. This finding shows that the government's intervention approach, which is informed by a focus on the individual patient, may not be relevant for hypertension management in Indonesia. The main theme that emerged from the analysis is 'the family as a dynamic system in mediating the control of hypertension'. This main finding is substantiated by four aspects: 1) the roles and responsibilities in the family, 2) the economic status of the family, 3) stresses and coping processes in the family, 4) the presence and absence of any hypertensive symptoms. The dynamic process of hypertension control is firstly influenced by the roles and responsibilities in the family, which in particular refers to each patient's roles and responsibilities as a grandparent and as a member of wider social systems. Secondly, the economic status of the family was found to be a significant aspect of family dynamics that often obliged the participant patients, as well as the other family members, to compromise their diets. Thirdly, hypertension control was dynamic because of stresses and the coping process, as this research has revealed the family can be both the sources of stress and relief for

individuals. Lastly, the family members' support was triggered only in the presence of a patient's hypertensive symptoms.

Conclusion: Decisions that individual family members make to control hypertension are made within the context of wider family dynamics, including the prescription of medication, diet, undertaking physical exercise, and the management of stress. This study pointed out the various processes in the family have challenged the patients' ability to control hypertension. Thus, to have an understanding of a family's readiness to provide care at home is important in order to improve illness management and prevent relapses. This study's results can be interpreted as an evaluation of non-communicable diseases (NCDs)-related policies and associated regulations. Evaluations are needed to ensure NCDs management related improvements to mitigate health inequalities in Indonesia.

Keywords: Hypertension, family, family system, focused-ethnography, Indonesia

Lay Summary

Background: High blood pressure is understood to be a lifestyle disease and is most commonly experienced in adulthood. The percentage of individuals in Indonesia aged ≥ 18 years identified with high blood pressure in 2018 was 34.1% (Indonesian Ministry of Health, 2018). In 2012, high blood pressure was recognised as a major cause of hospitalisation in Indonesia, with heart disease and stroke being the main reasons for deaths in hospital (Centre for Data and Information, 2012). The current high blood pressure management in Indonesia follows the Ministry of Health, Republic Of Indonesia's guidelines and focuses on the individual patient. The individual approach to high blood pressure control may not be relevant if families have a significant influence on daily practices relevant to the patient's well-being and all matters of particular relevance to those members who are affected by hypertension (Tull et al., 2013; Ribeiro et al., 2011). Family life in Indonesia reflects family structure involving several generations all living in one house. Given the importance of such a family structure and family life, daily high blood pressure management often goes beyond the patient and includes other family members, such as the spouse, children (adult and dependent) or grandchildren. It is this complexity and interaction within and between family members that required an in-depth study to investigate how patients and their families handle the day-to-day management of high blood pressure and this is the unique contribution of this study.

Aim: The aim of this study is to understand families' experiences in the daily management of one or more of its members' hypertension in Denpasar

Methodology: Qualitative research was conducted, and data was collected from eleven families in Denpasar through interviews and observations. The participant observations were carried out between February – July 2016 at the families' premises, clinics, and parks in Denpasar. The information obtained was compared and contrasted against each family, using Coffey and Atkinson's (1996) approach to analysing qualitative data.

Findings: The results showed there were frequent changes of care that were influenced by the roles and responsibilities of the patients within the family, the financial situation of the family, the levels and sources of stress from within the family as well as from outside, the family's general well-being and the symptoms of high blood pressure. The roles and responsibilities of the patients sometimes can hinder, but at other times boost, their care. Both wealth and poverty can lead patients' ability to choose less healthy foods. Furthermore, this research links increased levels of stress with increases in blood pressure. This study shows family members can trigger the rise in a patient's blood pressure through stress as well as being able help the patients to reduce their stress levels. Lastly, the study captured insights into the times when family members provided care when patients' symptoms were present, such as having a headache. This study highlights the influence of family relationships in high blood pressure care.

Conclusion:

Family members influenced the patients' decisions relating to taking medication, doing regular exercise, and managing stress. Various processes experienced by the family members in the family quite possibly created difficulties for the patients' attempts to control their blood pressures. Thus, it is important to have an understanding of the family's readiness to provide care at home in order to improve the patient's illness management and to prevent relapse. This study may help the government of Indonesia not only to evaluate the current policies in chronic disease management, but also to minimise health inequalities.

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List of abbreviations

BPJS	<i>Badan Penyelenggara Jaminan Sosial</i> or the Social Insurance Administration Organisation
CDC	Centers for Disease Control and Prevention
CVD	Cardiovascular disease
FAO	Food and Agriculture Organization
FCTC	Framework Convention on Tobacco Control
FFAM	Friedman Family Assessment Model
GST	General system theory
HBM	Health Believe Model
Int\$	International dollar
JKN	<i>Jaminan Kesehatan Nasional</i> or National Security System
JNC	Joint National Committee
MmHg	Millimetre of mercury
MoH	Ministry of Health
NCDs	Non-communicable diseases
PAHO	Pan American Health Organization
PBC	Perceive Behavioural Control
PMT	Protection motivation theory
Prolanis	<i>Program Pengelolaan Penyakit Kronis</i> or Chronic diseases management program
Puskesmas	<i>Pusat Kesehatan Masyarakat</i> or Community Health Centre
TPB	Theory of Planned Behaviour
WHO	World Health Organisation

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1 Introduction

1.1 Introduction

Hypertension is a global public health issue which contributes to the development of heart disease, stroke, kidney failure, premature death and disability (WHO, 2013, James et al., 2014, Krakoff et al., 2014, Whelton et al., 2018). In response to this threat, global and national agencies have developed and kept updating health promotion strategies, hypertension management related policies, and guidelines to control hypertension in order to reduce or prevent its potential to cause further disabilities (Whelton et al., 2018, James et al., 2014, WHO, 2013, WHO, 2013a). These efforts have resulted in declining levels of hypertension in high income countries, but the condition's prevalence has been increasing in low and low-middle income countries (Mills et al., 2016).

Insufficient resources and progressive demographic changes in low and lower-middle income countries have become very important issues for these nations to take into account in order to effectively tackle the burdens caused by non-communicable diseases (NCDs) such as hypertension; the latter being the focus of this study. Therefore, using self-management for dealing with NCDs, including hypertension, can be a cost effective approach to reducing the financial and healthcare burden among low and low-middle income countries (Deidda et al., 2018, Abaza and Marschollek, 2017, Mogre et al., 2017). On the other hand, self-management is predominantly influenced by the relationship of individuals with their families, as the family is the key to constructing an environment that is conducive to the implementation of self-management (Whitehead et al., 2018, Rosland et al., 2010). Family influence in self-management necessitates further understanding of the issues relating to hypertension control; particularly exploring the family

experiences in low middle income countries such as Indonesia, where this study was conducted.

I highlight the structure of the thesis and the focus of each of the other chapters in this first chapter. In addition, this introductory chapter discusses the rationale for the topic, the aims and objectives of the research, and the research questions.

1.2 The structure of the thesis

I follow the IMRAD format (Introduction, Methodology, Results and Discussion) as the structure of this thesis. The thesis comprises of eight chapters: 1) Introduction, 2) Literature Review, 3) Methodology, 4) Family Profiles, 5) Findings, and 6) Discussion, 7) Recommendations, 8) Conclusion. The following sections outline the focus of each chapter.

1.2.1 Introduction

In the first chapter or the Introduction chapter, I introduce the emergent global interest in hypertension and the importance of this study within the Indonesian context. The first chapter also outlines the research aim, objectives, and questions. In addition, this first chapter also introduces the main points that are covered in each chapter of this thesis.

1.2.2 Literature review

The second chapter is the Literature Review that discusses the main published points relating to hypertension and its control. In this second chapter I also review chronic disease management, specifically for hypertension within the family setting, with the discussion being based on empirical knowledge. Indonesia, as the study location, is an archipelagic country which has hundreds of ethnic groups and very diverse cultural backgrounds, represented in a population of more than 237 million people. The daily lives of Indonesians are predominantly influenced

by the traditional culture of their ethnic group. Thus, a review of Indonesian culture, religion and family is presented in this chapter, followed by a review focused on hypertension control in a family setting, together with an examination of the meaning of 'health' and 'illness' for Indonesians in general.

1.2.3 Study methodology

I discuss the methodology utilised in this study in Methodology chapter. The justification for using focused ethnography is presented along with constructionism as the epistemological stance and symbolic interactionism as the theoretical perspective of the methodology. Further the chapter elaborates on the sampling strategy, which includes the family as the unit of analysis. In addition, the iterative nature of data collection and data collection methods, observation and interviews, are described. The data analysis section is informed by the work of Coffey and Atkinson (1996), whose approach I chose as appropriate to answer the research questions. The data analysis process starts with a descriptive analysis, before moving into more meaningful categorisations, followed by generalising and theorising.

1.2.4 Findings

The study's results are divided into two chapters. The first chapter provides the context of families or family profiles based on the observation results as, for ethnographic studies, providing details of the basis of the information and the setting for the ethnographic fieldwork is very important. The second chapter presents a feedback loop diagram to portray the complexity of hypertension control in family settings within the Indonesian context. The diagram shows a family system's properties that play an important part in hypertension control, such as: 1) equifinality, 2) wholeness and 3) connectedness. In addition, the diagram also shows that disease symptoms significantly influenced the family members to take

part in hypertension control efforts in daily life. The main theme of this study, which includes family system theory, structure and agency concepts, as well as the theory of protection motivation, as the lenses through which to interpret the data. The results reveal that in Indonesian family settings, hypertension control is a dynamic process strongly mediated by 1) the roles and responsibilities within a family, 2) economic conditions, 3) stress and coping processes, and 4) the presence and absence of the symptoms of hypertension. Whilst families are often dynamic systems, cultural values can result in a rigid family format, thus posing barriers to hypertension control. However, the family is also a major factor that supports hypertension control in a patient's daily life; many aspects of hypertension control cannot be separated from the family's daily routines that involve other family members.

1.2.5 Discussion

In this chapter I discuss the essential elements in the main finding of this current study, as well as the importance of this study's findings when it comes to improving hypertension control in the Indonesian context. Family, as an open system, is self-regulated and reacts to input through a feedback process. The positive and negative feedback coming from family members potentially compromised or supported the patients' hypertension management. Furthermore, various aspects related to patients' interrelationships, interconnectedness and interdependence also presented barriers to hypertension management. I found that the individual patients frequently had less influence in controlling their blood pressure than did their family members. It was the latter group who exerted the strongest influence on the patients' hypertension control. Therefore in this chapter, I address the importance of considering the family as a system approach in health promotion and disease prevention.

1.2.6 Recommendations

In this chapter I explain study's main contribution for practice improvement, which targeting institution and patient-provider level. In addition, based on this study findings I also recommend the importance of future research in the areas of: 1) decision making in health care within intergenerational families, 2) family-related health policies development, 3) families' experiences for biomedical and alternative treatment, 4) cross-cultural patient-provider experiences in community setting, 5) health interventions for family's health improvement, and 6) evaluation of family approach in chronic disease management.

1.2.7 Conclusion

This section emphasises the importance of including families in hypertension control and provide hypertension control information for family members. In the Indonesian context, the family members are the closest resource for a patient with a chronic condition such as hypertension; whilst the family may not provide all the resources needed, the members will be the first to respond to a family member's health issues. However, family members have different perceptions related to hypertension; as a system a family can be both adaptable and/or rigid and thus act either as a barrier and/or a facilitator for patients, when attempting to control hypertension.

In the next section I elaborate the significance of hypertension to global public health.

1.3 The significance of hypertension to global public health

Hypertension is an important determinant in the development of cardiovascular diseases (CVDs) (Kagan, 1959, WHO, 2017, Franklin and Wong, 2013, Global Burden of Disease Study Collaborators, 2015). As the leading cause of cardio-vascular disease (CVD), hypertension is also responsible for premature

deaths and disability worldwide (Global Burden of Disease Study Collaborators, 2015). The most recent data shows 17.9 million people died from CVDs in 2016, and this number equals 31% of global deaths, thus making CVDs the number one cause of death globally (WHO, 2017). Hypertension and deaths due to CVDs mainly take place in low and lower-middle income countries, rather than in the wealthier ones (Cifkova et al., 2010, Global Burden of Disease Study Collaborators, 2015, Kastarinen et al., 2009, Devi et al., 2013, Li et al., 2012, Addo et al., 2007, Danaei et al., 2011). The low and lower-middle income countries are those nations with gross national incomes (GNI) per person of $\leq \$ 995$, and $\$996 - \3895 respectively. Upper-middle and high income countries are those with a GNI per person of $\$3896 - \12055 and ≥ 12056 respectively, based on World Bank classification in 2017 (World Bank, 2017). In 2010, 31.1% of the world's adults aged ≥ 20 years had hypertension (Mills et al., 2016). Meanwhile the age-standardized prevalence of hypertension was 28.5% in higher income countries, and reach 31.5% in low and lower middle income countries (Mills et al., 2016). Mills et al. (2016) also suggested that the prevalence of hypertension steadily declining from 2000 – 2010 in high income countries, but at the same time was increasing in low and lower-middle income countries.

The increase in hypertension worldwide is associated with a number of factors including: 1) increases in the elderly population, 2) the increase of sedentary behaviour in daily life, 3) changes in diets and 4) stress resulting from the impact of modern life (WHO, 2013). In addition, the fifth factor is the new guidelines that present a new classification of hypertension; a move that has also increased the prevalence of hypertension worldwide (Whelton et al., 2018). Factors 1), 2), 3) and 4) are elaborated in the following sections.

1.3.1 The increasing elderly population

The increasing elderly population is the first factor to be addressed in this section. The number of elderly has progressively increased; globally the number of people aged 65 or older is projected to grow from 524 million in 2010 to nearly 1.5 billion in 2050, with developing countries experiencing the greatest proportion of this increase (National Institutes of Health, 2011).

A better health care system strongly relates to increases in life expectancy; however, the longer life expectancy is not necessarily followed by a healthy lifespan, due to a person's physiological decline (Kanasi et al., 2016, Fehlings et al., 2015, Lionakis et al., 2012, Kline and Bowdish, 2016, Del Giudice et al., 2017). Patho-physiological changes in blood vessels, kidney, neuro-hormonal and autonomic regulatory functioning cause the increase of blood pressure among the elderly (Lionakis et al., 2012). Lionakis et al, (2012) make the point that arteries' elasticity changes with age, as the vessels dilate and stiffen, resulting in those vessels being unable to accommodate the changes during the cardiac cycle. *Meanwhile, aging kidneys* are characterised by the progressive development of glomerulosclerosis and interstitial fibrosis, which then cause declining GFR (Glomerular Filtration Rate) and negatively affect the homeostatic mechanism (Beck, 2000). Additionally, the activity of membrane sodium/potassium and calcium adenosine triphosphate pumps in the kidney influence the organ's vasoconstriction and vascular resistance (Buford, 2016, Lionakis et al., 2012). The neuro-hormonal and autonomic regulation efficiency levels also deteriorate due to the aging process. The neuro-hormonal renin-angiotensin-aldosterone system (RAAS), which regulates the cardiovascular function, declines with age, and it is also associated with the development of hypertension (Femminella et al., 2013, Carthy, 2013). All those changes cited above significantly increase the risk of the elderly developing hypertension, which in turn is likely to lead to the development of cardiovascular disease.

The aging population is a global issue; however, the increase of the elderly population numbers is most challenging for low and lower-middle income countries, because their numbers are growing faster than in higher income countries (United Nations, 2017). As individuals age they tend to need long term care due to functional impairment and disabilities, which in turn increases the health care cost. However low income nations are often unable to provide the economic means to cope with the social and economic challenges posed by this profound demographic change (Lee, 2010).

Other than the patho-physiologic changes among the elderly that increase the hypertension prevalence worldwide, changes in lifestyle are also known as a *determinants* of hypertension; a point which is discussed in the following section.

1.3.2 The increase of sedentary behaviour in daily life

Sedentary behaviour refers to minimum levels of physical activities that are related to low energy expenditure, counted at 1.0-1.5 metabolic equivalent units (METs) (Pate et al., 2008). Activities corresponding to sedentary behaviour include sitting, and watching TV or reading a book, lying down, and other forms of screen-based work and entertainment (Pate et al., 2008, Katzmarzyk, 2010, González et al., 2017). The relationship between the increase of an individual's blood pressure and sedentary behaviour is because the increased consumption of high-calorie foods contributes directly to increased caloric intake during the sedentary activities (such as watching TV), and the accompanying increase of a person's body weight inevitably increases their blood pressure (Christofaro et al., 2015, Chaput et al., 2011, Fernandes et al., 2011). The occupations for many in the 21st century, particularly 'office workers', require individuals to spend their 7-8 hours working days sitting; for example working on computers and attending meetings (Murphy, 2015). Due to this fact, sedentary behaviour has become a global public health issue, as

globally 23% adults, aged 18 and over, were insufficiently active in 2010 (WHO, 2018e).

Both in lower and higher income countries people are getting ever more physically inactive; in the USA 1 in 4 white adults spend about 70% of their waking hours sitting (Owen et al., 2010). Meanwhile, in lower income nations such as in some African countries, youths and adults failed to have 30 minutes of moderate intensity physical activity on at least 5 days a week, 20 minutes vigorous intensity physical activity on at least 3 days per week, or an equivalent combination achieving 600 MET-min per week (Larouche, 2014, Hallal et al., 2012). More people are becoming engaged in sedentary behaviour a) because the increased use of motorised travel forms, such as cars, trains and buses, together with b) higher economic status, which results in greater engagement with screen time entertainment, such as watching TV (Larouche, 2014).

Additionally Laslett et al. (2012) add urbanisation also contributes to sedentary behaviour and lack of exercise. Major ways that the urbanisation contributes to lack of physical activity include: 1) poor environmental condition due to pollution, 2) high traffic, 3) poor facilities such as no sidewalks, and 4) the threat of violence outside the home (Laslett et al., 2012).

One of the main impacts of sedentary behaviour is obesity, which is related to the increase of blood pressure. Obesity is a complex issue, as it is complicated by various bio-socioeconomic factors; however, the most important factor determining the prevalence of obesity that needs to be discussed in relation to hypertension is the changes in people's diets. The following section discusses this issue in relation to obesity and hypertension.

1.3.3 Changes in diets

Poor diet has been recognised as an important determinant in the prevalence of hypertension (Anand et al., 2015, Forouzanfar et al., 2016, Slater et al., 2010, Ibrahim and Damasceno, 2012). Poor diet causes obesity, which results in an abnormal accumulation of body fat (Crawford et al., 1999). The fat or adipose tissue and other factors such as neuro-hormonal pathways, metabolic functions and modulation of pressor/depressor mechanisms work in collaboration, or overlap, increasing the blood pressure (Kotsis et al., 2010). The WHO (2018d) records in 2016 more than 1.9 billion adults aged 18 years and older were overweight, and 650 million of these were obese. Put another way, the number of obese adults worldwide has tripled since 1975. In relation to food transition, the obesity is caused by the increased consumption of high calorie foods such as dairy products, carbohydrates and animal source foods, which replace diets rich in legumes, vegetables and coarse grain (Anand et al., 2015, Popkin et al., 1996, Imamura et al., 2015).

In wealthy countries such as the US, higher income, higher socio economic status (SES) used to be associated with obesity; however, this situation has changed overtime as populations who are living 'below the poverty line' now have the highest rates of obesity (Hruby and Hu, 2015, Levine, 2011). The shifting role of income in obesity is strongly linked to a person's education level, as education can act as a protective factor in the prevalence of obesity (Hruby and Hu, 2015). Similarly in low and lower-middle income countries, the pattern has been mimicking the obesity-SES patterns in higher income countries; people with lower SES have higher rates of obesity than their counterparts with higher SES (Hruby and Hu, 2015, Popkin and Slining, 2013).

In modern life, as foods become more affordable and readily available, this condition could activate addiction circuits in the human brain (Seaman, 2013). Therefore, Seaman (2013) adds that becoming overweight or obese in current

modern life is 'inevitable' unless individuals are educated to actively engage in activities that prevent weight gain.

Another important aspect of diet that has been correlated with increased blood pressure is salt (Hashem et al., 2015, Noubiap et al., 2015, Aviv, 2001, Wyness et al., 2012, DiNicolantonio and Lucan, 2014, Batuman, 2013). Consumption of more than 2 grams of sodium per day, or 5 grams of salt per day, combined with insufficient potassium intake (3.5 grams/day), contributes to high blood pressure and increases the risk of CVD (WHO, 2016). Excess salt intake would increase blood pressure due to the elevation of cardiac output and/or peripheral vascular resistance (Aviv, 2001, Takeshita et al., 1982, Sullivan and Ratts, 1988, Guidi et al., 1996). Global salt consumption has increased steadily during several decades to 18 g/day worldwide and this increase is consistent with the increase of hypertension prevalence to 25% in adult aged > 25 years old worldwide (Batuman, 2013).

A reduction of salt intake to 6 g/day is associated with a reduction in systolic/diastolic blood pressure of 7/4 mmHg in people with hypertension and 4/2 mmHg in those without hypertension (DiNicolantonio and Lucan, 2014). Reducing salt intake is one of the most cost effective interventions to tackle hypertension and any further morbidity and disabilities it might cause. For this reason the WHO has targeted a 30% global reduction in salt intake by 2025 (WHO, 2016). Even though programmes for salt reduction are in place, many challenges are faced by the low and lower-middle income countries to reach the target of 30% salt reduction by 2025 (Newson et al., 2013, Trieu et al., 2015). Trieu et al. (2015) report that less than half of the salt reduction programmes were implemented in low and lower middle income countries, due to poor monitoring and low coverage. Meanwhile the low and low middle income countries are still projected to experience the greatest burden

caused by NCDs, where 78% of NCD deaths and 85% of premature deaths occurred (WHO, 2018c).

Meanwhile, modern life has not only changed the diets of the world's population, it has also increased the levels of stress experienced by that population. Significantly, stress is acknowledged to be an important determinant of hypertension. The correlation between stress and hypertension is discussed in the following section.

1.3.4 Modern life as the major stressor

Acute stress is related to future blood pressure status, heart hypertrophy and atherosclerosis, as stress triggers the reactivity of systolic blood pressure, diastolic blood pressure and heart rate (Wright et al., 2014). Stress has been associated with people's moves to urban areas, often from quieter, simpler, slower rural ones; not only a demographic movement but also a change in a person's social, economic and psychological conditions (Srivastava, 2009). Urbanisation is a part of modern life that has a two edged effect on health: 1) positively, urbanisation benefits people because they can easily access healthcare services, sanitation, and nutrition; however 2) negatively, urbanisation causes overcrowding, pollution, social deprivation, increased crime and stress related illness, as well as a disconnect from the family elders who may not have moved (Godfrey and Julien, 2005). Globally more people prefer to live in urban areas than rural areas, as the latest data shows 55% of the world's population are now residing in urban areas (United Nations, 2018). The percentage will steadily increase, with the United Nations (2018) projecting that by 2050, 68% of world's population will be living in urban areas.

Life in urban areas gives the experience of living in a multicultural environment which contributes to increased tolerance, a better quality of life (health improvement) and sociocultural stimulation (Moore et al., 2003). However, these

same conditions often contribute to heightened social tensions, interethnic striving and cultural conflicts, issues which inevitably increase stress levels (Trivedi et al., 2008). The inevitable increase in stress levels, as more people move to urban areas, will correspondingly contribute to the global increase in hypertension.

Other than the demographic changes, and lifestyle transition, the increase of hypertension worldwide is also influenced by the latest hypertension guidelines launched by the American College of Cardiology (ACC) and American Heart Association. These guidelines set a new classification for hypertension, which is discussed in the following section.

1.3.5 The new hypertension classifications

The classification of hypertension is not uniform throughout the world. The latest guidelines were launched in 2017 by the American College of Cardiology (ACC) and the American Heart Association (AHA): the “ACC/AHA Guideline” (Whelton et al., 2018) . The 2017 ACC/AHA guidelines lower the bar for diagnosis of hypertension, and categorised blood pressure in adults as the following:

1. *normal*: when the systolic blood pressure (SBP) <120 mmHg and diastolic blood pressure (DBP) < 80 mmHg,
2. *elevated*: if the SBP 120-129 mmHg, and the DBP 80 mmHg,
3. *hypertension stage 1*: if the SBP 130 – 139 mmHg or the DBP 80 – 89 mmHg,
4. *hypertension stage 2*: if the SBP \geq 140 mmHg or the DBP \geq 90mmHg (Whelton et al., 2018).

Meanwhile the categorisation of blood pressure for adults is based on the earlier guideline released by the Joint National Committee for Hypertension (7th Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure). Blood pressure is classified as:

1. *Pre-hypertension* if the SBP is 120 – 139 mmHg, and DBP 80-89 mmHg,

2. *Hypertension stage 1* when the SBP is 140-159 mmHg, and the DBP is 80 – 99 mmHg,
3. *Hypertension stage 2* when the SBP \geq 160 mmHg, and the DBP is \geq 100 mmHg (Chobanian et al., 2003, Ministry of Health Republic of Indonesia, 2015).

The 2017 guidelines that are used in wealthy countries have categorised more people as hypertensive and therefore more medication is needed for those people; thereby creating more expense for healthcare systems and more profits for pharmaceutical companies (Watkins, 2018, Dyer, 2017, Muntner et al., 2018). However, the 7th report of the Joint National Committee is still widely used in lower income countries such as in Indonesia (Ministry of Health, 2015).

The implication of the ACC/AHA 2017 guideline is the creation of substantial increases of hypertension prevalence in high income countries, and double the prevalence of hypertension in low to middle income countries (Whelton et al., 2018, Muntner et al., 2018, Watkins, 2018, Vidal-Petiot et al., 2018, Mancia and Corrao, 2018). If the ACC/AHA guidelines are implemented many people will be shifted from the normal and pre-hypertension stages to the advanced stages (1 and 2), suggesting that the demand for pharmacotherapy would greatly increase (Watkins, 2018). The ACC/AHA 2017 guidelines are expected to increase awareness and encourage lifestyle modification, as well as focus on medication initiation (Muntner et al., 2018). Implementing the new guidelines in low-middle income countries may not have the same potential as in high income countries, in terms of raising the awareness, increasing disease control through medication and implementing healthier lifestyles. The challenge arises because there are huge gaps of awareness and disease management between high income countries and low-middle income countries. The population in high income countries in comparison to low-middle income countries were more aware of their blood pressure (67.0% versus 37.9%),

more people treated their hypertension (55.6% versus 29.0%) and more people control their blood pressure (28% versus 7.7%) (Mills et al., 2016). Thus, the new guidelines might present a big challenge for low-middle income countries; not only is hypertension prevalence doubled, but also there are the issues of resource scarcity and the population's poor levels of awareness, treatment and control of the causes and the condition of hypertension.

Hypertension as an important global public issue due to the problems it causes for the global population. These problems are projected to steadily increase due to global demographic transitioning, lifestyle changes, diet changes, urbanisation and the new hypertension guidelines. Global agencies, such as the WHO, have continuously updated their guidelines and data, in order to encourage and provide assistance for countries to enhance their public policies to tackle NCDs, such as hypertension, with a view to reducing the morbidity and mortality caused by those NCDs (Whitworth and Chalmers, 2004, WHO, 2013, WHO, 2011). However, the low and lower-middle income countries are the most vulnerable in tackling the NCD pandemic compared to higher income countries which, most of the time, succeed in mitigating the impact of NCDs (Mills et al., 2016). Generally the low and lower-middle income countries are affected the most by the increase of NCDs, including hypertension, due to resources scarcity, poor programme implementation, poor monitoring, huge populations with various socioeconomic issues, wide coverage areas and poor health care facilities (Allotey et al., 2014, Lagomarsino et al., 2012, Chow et al., 2013, O'Donnell et al., 2008). To achieve the best results, even when hindered by severe resource limitations, the low and lower-middle income countries are encouraged to increase cost effective interventions, such as by shifting basic care from centralised urban medical facilities out to communities or homes (Watson et al., 2018, Vaughan et al., 2015, Shillcutt et al., 2009, Lewin et al., 2008).

Fortunately cost effective and high impact interventions are available, and can be implemented at the individual level in the form of self-management, which cost almost nothing (Narain, 2011). However, self-management is strongly influenced by the relationship of the individual patients with their families, as the family is the key to constructing an environment that is conducive to the effective implementation of self-management (Whitehead et al., 2018, Rosland et al., 2010). Therefore, the influence of family to self-management necessitates further understanding of the issues relevant to hypertension control, exploring particularly the family experiences in lower- middle income countries, such as Indonesia, where this study was conducted; a focus chosen because the situation of NCDs is likely worsen in these countries. Moreover, this study's findings and implications can be utilised as a reflection for other countries with multicultural backgrounds to improve their services regarding hypertension and or NCDs management.

1.4 The significance of the study from the Indonesian perspective

This study was conducted in Indonesia, an archipelagic country located in South East Asia that lies between the Indian and Pacific oceans. Based on the latest census in 2010, the population of Indonesia is 237,641,326, and is projected to reach 271,066,400 in 2020, comprising of 633 ethnicities; numbers which make the country the 4th most populous country in the world (Statistics Indonesia, 2013, Statistic Indonesia, 2018). Indonesia currently is still experiencing demographic transition because: 1) the country has more proportion of population age 15-64 years old (66,5% in 2010), 2) birth rate is decreasing (from 2.6 in 2012 becomes 2.4 in 2017), 3) increasing life expectancy (70.1 years in 2010, and it is projected to reach 72 years in 2025), and 4) increasing number of population aged >65 years old (7,56% in 2010 and is projected to reach 11,83% in 2025) (Statistic Indonesia, 2018). The demographic transitions have been associated with healthcare

improvements in the country, including the care system itself, financing, facilities, and increased interventions in health promotion and disease prevention (Adioetomo, 2014, Mboi, 2015). Despite the healthcare improvements in place, the risk factors such as: i) demographic transition, ii) the increase of GDP per capita, iii) globalisation, iv) urbanisation, v) changes in diets, vi) more sedentary lifestyle, and vii) the high prevalence of smoking have created more issues related to NCDs. These issues in turn create ever greater burdens for Indonesia's healthcare and economic resources. However, it is important to point out that the majority of those risk factors are actually modifiable and open to self-management; such as diets, physical activity, and smoking behaviour.

As life expectancy is increasing and the numbers of the elderly increase, the morbidity and mortality rates caused by degenerative diseases or NCDs are also increasing, while the country is still struggling with communicable diseases (Ministry of Health Republic of Indonesia, 2016b). As a result of these circumstances, Indonesia is a country with a double health burden: 1) an emerging epidemic of non-communicable diseases, together with 2) persistent communicable diseases. The latter burden includes: a) outbreaks of common infectious diseases, b) re-emerging infectious diseases and newly-emerging infectious diseases such as c) malaria, d) dengue fever, e) influenza, f) HIV/AIDS and g) respiratory diseases. This double burden has created serious challenges for the country's health care system, which is finding such a situation increasingly difficult to deal with (Department of Health Republic of Indonesia, 2010, WHO, 2015). Furthermore, the rapid demographic changes impacting on NCDs' prevalence are occurring during periods of politic instability that are negatively affecting both economic and social contexts (Van Eeuwijk, 2006, Slater and Simmons, 2012, Fossati, 2016).

For income, Indonesia is classified as a lower-middle income country, with the GDP per capita having steadily risen from \$857 in 2000 to \$3847 in 2017 (World

Bank, 2018b). However, a wide inequality gap regarding income distribution has been recorded between the rural and urban areas; many of the people in rural areas are significantly poorer than those in urban areas (Wicaksono, 2017, Akita, 2011). The incidence of increased urbanisation has contributed to this inequality, as 55% of Indonesians now reside in urban areas (Statistic Indonesia, 2018). A combination of increase incomes and urbanisation has been linked to the transition of diets among Indonesians (Cyril et al., 2013, Gerbens-Leenes et al., 2010, Godfrey and Julien, 2005, Ibrahim and Damasceno, 2012). The increasing incomes of Indonesians have been followed by the increasing demand for foods in general, especially animal-sourced foods such as meat, dairy products, eggs and fish (Abler, 2010, Molyneaux and Rosner, 2004). In addition, more than half of Indonesians' financial resources will be spent on food (World Bank, 2018a). Economic growth, which may be seen as desirable and positive, represents the main contributor to the incidence of hypertension in Indonesia. This negative outcome to what some may perceive as progress, is partly due to the fact that increased fat intake and more diverse diets have shifted trends from dietary deficit and food insecurity to over consumption. This stereotype of 'economic progress' has inevitably led to obesity, which constitutes a major risk factor for NCDs (Lipoeto et al., 2013, Ismoyowati, 2015, Popkin et al., 2012, Roemling and Qaim, 2012).

Additionally globalisation, in combination with rapid economic growth and urbanisation, has played an important role in the nutritional transition in Indonesia, with Indonesians now preferring processed foods that are rich in salt, sugar and saturated fats, rather than wholesome home-cooked foods (Baker and Friel, 2014). Processed foods that are frequently consumed by Indonesians include: i) noodles, ii) ice cream, iii) chocolates, iv) cheese, v) oils and vi) fats. These kinds of foods have been linked to the prevalence of obesity and diet-related NCDs including hypertension (Wang and Zhai, 2013, Khandelwal and Reddy, 2013, Chavasit et al.,

2013, Ramachandran et al., 2010). Processed foods are now preferred, at least by urban dwelling Indonesians, because the foods are convenient, and manufactured using global recipes, which are then adapted and marketed to appeal to local tastes and consumer preferences (Hawkes, 2007, Hawkes, 2006).

The diet transition of the Indonesian population is strongly associated with the prevalence of overweight/obesity (Department of Health Republic of Indonesia, 2013, Rachmi et al., 2016, Rachmi et al., 2017). The prevalence of obesity in Indonesia is alarming, especially among Indonesian women, as the increase of its prevalence surpassed the prevalence of women obesity globally within less than half of the global time frame (Rachmi et al., 2017). The increased obesity among Indonesian men and women during 1993 to 2007 (14 years) was 11% and 16 % respectively, meanwhile obesity globally within 33 years (1980 – 2013) arose 8.1% in men and 8.2% in women (Rachmi et al., 2017, Roemling and Qaim, 2012, Popkin and Slining, 2013, Ng et al., 2014). The high prevalence of obesity in Indonesia is exacerbated by the low levels of physical activity (Rachmi et al., 2017). According to the WHO (2018a) record 22% of the Indonesian population, aged >18 years, were physically inactive in 2016.

Another modifiable risk factor that has been reported as a major cause of non-communicable diseases, especially cardiovascular disease, cancer and hypertension, is smoking (WHO, 2012). Despite the global and in-country warnings the prevalence of smoking in Indonesia is increasing (Department of Health Republic of Indonesia, 2013, WHO, 2018a). The smoking prevalence in 2010 was 34.7% of the adult population, according to the Department of Health, Republic of Indonesia (2013). This number had increased to 39% in 2016 (WHO, 2018a). The high prevalence of smoking in Indonesia is also associated with cheap cigarettes; cigarette taxes are very low when compared to other countries. Economic growth makes the habit of smoking more affordable for everyone, especially the young and

relatively poor (Asian Pacific Pediatric Association, 2012). Despite the fact that cigarettes are more affordable for lower income households, the incidence of smoking between lower and higher income individuals in Indonesia is very similar across the expenditure categories (Barber and Ahsan, 2009).

The risk factors associated with NCDs lie behind the statistic that premature deaths from NCDs reached 73% of total deaths in 2016, with 35% of mortality caused by cardiovascular disease, the main NCD (WHO, 2018a). Hypertension has been widely accepted as one of the major underlying conditions for the development of stroke and cardiovascular disease (Whelton et al., 2018); thus, hypertension plays a *central* role in increasing morbidity and mortality rates in Indonesia. The prevalence of hypertension in Indonesia, among individuals aged ≥ 18 years old in 2018, was 34.1% (Ministry of Health Republic of Indonesia, 2018). The prevalence of hypertension in Indonesia has increased from 25% in 2013 to 32.4% in 2016 (Ministry of Health Republic of Indonesia, 2016b). In Indonesia, the most recent data shows hypertension is a major cause of hospitalisation, whereas cardiovascular diseases and stroke were the main reasons for deaths in hospital (Centre for Data and Information, 2012). Moreover, there are 59.8% of patients identified with hypertension who are not receiving adequate treatment; this unsatisfactory situation leads, almost inevitably, to advanced organ failure in many of these patients (Ministry of Health Republic of Indonesia, 2018).

Adopting and maintaining a healthier behaviour, such as: 1) diet interventions relating to the control of both quantity and quality of food intake, 2) quitting smoking, 3) reducing alcohol consumption, 4) reducing weight for those with BMIs ≥ 29.5 and 5) doing regular exercise, make up the central interventions proposed, in order to facilitate hypertension management. These interventions have been encouraged in order to maintain blood pressure at $<140/90$ mmHg (WHO, 2013, Bosworth et al., 2008, Pongwecharak and Treeranurat, 2011). Similar to other chronic conditions,

blood pressure control requires self-management by the patients. Researchers have suggested that when patients take control of managing their chronic conditions, that action will result in 1) better treatment outcomes, 2) less hospital admissions and 3) higher levels of self-efficacy (Lorig et al., 2001, Thoolen et al., 2007, Schreurs et al., 2003).

In Indonesia, the Ministry of Health launched hypertension management guidelines for use in primary care settings; especially public health care (PHC) clinics. The latest update of the guidelines is The Ministry of Health Republic Of Indonesia Decree Number HK. 02.02/Menkes/514/2015, titled: "Clinical Practice Guidelines for Doctors on Primary Health Care Services" (Ministry of Health Republic of Indonesia, 2015). The guidelines are provided for medical staff at PHCs for most common diseases in the community, including hypertension. The protocol for hypertension in the document is very brief; its reference was the previous guideline book that was launched in 2013 by the Ministry of Health, Republic of Indonesia. The national protocol for hypertension consists of: 1) controlling risk factors, 2) pharmacological treatment, 3) follow-up interventions and 4) early detection of complications associated with hypertension (Ministry of Health Republic of Indonesia, 2013).

In addition, a healthier lifestyle is recommended for controlling hypertension's risk factors. Keeping the nutrient's balanced, and ensuring reduction of sugar, salt and fat consumption, based on Dietary Approaches To Stop Hypertension (DASH) (Conlin, 1999) are advised. The protocol also encourages the medical staff to educate patients in how to: 1) maintain their ideal weight and waistline, 2) exercise regularly, 3) quit smoking and 4) limit their alcohol consumption. For the pharmacological treatment, the guidelines predominantly explain the combination of the drugs for each stage of hypertension. The latest guidelines (Ministry of Health Republic Of Indonesia Decree Number HK. 02.02/Menkes/514/2015) also contain

very brief information related to diets and pharmacological treatment. The 2013 document provides information about foods and quantities allowed, but this information is not included in the updated document. The previous document in 2013 also encouraged medical staff to include individuals and their family members in initiatives to control diets. However, the latest 2015 document makes no mention of family members as contributors to lifestyle improvements. The health education that takes place, perhaps incidentally, in consultation rooms is mainly targeting individuals.

Meanwhile, families have a huge influence on daily diets; they influence the food options, the dietary intentions and adherence to diets, which are all matters of particular relevance to those members who are identified with hypertension (Tull et al., 2013, Ribeiro et al., 2011). Similar to diets, the family represents a significant determinant of treatment adherence among patients with chronic conditions. Mayberry and Osborn (2012) found that there is a chance that the family might sabotage the patient's efforts to perform treatment adherence behaviour, so they suggested informing the family members about the treatment to enhance the motivation and behavioural skills of the patient, as well as his or her management outcomes. Meanwhile, Miller and DiMatteo (2013) suggested that for patients with a chronic condition, their families can provide practical assistance and can buffer the stresses that come from living with illness. The researchers concluded that family support is an essential factor influencing the patient's adherence to his / her treatment regimen.

Meanwhile, both of Indonesia's guidelines on hypertension management fail to give clear advice on how to improve patients' adherence to treatment; nor do the documents address the issue of alternative interventions for lifestyle improvements. The treatment adherence cannot be solved only by giving education, because non-adherence to a medication regimen is a complex and multidimensional health care

problem. Whilst providing appropriate education is an attractive intervention but it may not fit or be suitable for all patients (Hugtenburg et al., 2013, Pasina et al., 2014, Marcum et al., 2013). Thus, medical staff need to assess the causes for the patient's non-adherence, and tailor a solution that fits that particular patient's situation (Hugtenburg et al., 2013). As researchers have suggested, behavioural change is unlikely to happen in a context where it is only influenced by an individual; there is evidence to suggest that any such change is also influenced by an individual's social network (Berkman et al., 2000, Bodenheimer et al., 2002, Hogan et al., 2002, Gorman and Sivaganesan, 2007).

Support from a social network, especially family, is one of the most successful ways of increasing a patient's self-management behaviour, but that support could also exert a negative impact on disease management if it is misdirected (Baker et al., 2003, Kiernan et al., 2012, Cornwell and Waite, 2012). Thus, the availability of constructive social support needs to be ensured in order to achieve improved self-management, as self-management can inform healthy behaviour, both in more or less favourable circumstances (Abaza and Marschollek, 2017, Abdulrehman et al., 2016, Audulv et al., 2012, Deidda et al., 2018, Glynn et al., 2015, Jonsdottir, 2013). Since most families can influence a member's disease management, identifying their perspectives of the disease, as well as the barriers and facilitators of that management model, would be helpful in exploring and thus understanding how hypertension management works in families, as well as how this model might be improved or supported. Therefore, including family members in any discussions or programmes relating to chronic condition management is, or should be, a priority. Families can be viewed as a system in which elements of the family are interconnected to and influenced by each other (von Bertalanffy et al., 2015, Denham, 2003, Broderick, 1993). When perceived as a health-promotion environment, the family is referred to as:

“a complex site for reception, transmission and communication of health information. Individual health beliefs and health related behaviour are related to a number of factors related to family.” (Holland et al., 1996, p.83)

Moreover for Indonesians the reception, transmission and communication of health-related information are expected to be complex, as intergenerational living arrangements are still preferred. The family is the most important social support resource for individuals, as well as an important unit in the community (Keasberry, 2001, Johar and Maruyama, 2011, Schröder-Butterfill, 2004). One of the main values shared by Indonesian families is that family members have reciprocal obligations to care for each other. This obligation, even duty, can be seen as a positive influence on chronic condition management, especially hypertension. There are very few studies in Indonesia that attempt to explore the whole family's experience in hypertension management; the majority of the researchers merely focus on one family member, either the patient or the member who is appointed to be the patient's primary carer (Hussain et al., 2016, Sohn, 2015, Widjaja et al., 2013, Christiani et al., 2015, Kisjanto et al., 2005). Therefore, the family's experience as a *unit of care* in hypertension management remains unclear.

This study is focused on Denpasar, the capital of Bali province. Denpasar was chosen as the study location because it has become the cultural centre for education, trade and tourism, which attracts people from other provinces in Indonesia, thus creating a multicultural environment which portrays the diverse social conditions of Indonesia.

1.5 The aim, objective, and questions of the study

This study aims to set out the families' experiences in daily hypertension control in Denpasar, Bali, Indonesia. The study is carried out among patients who are identified with hypertension and their family in Denpasar.

1.5.1 The objectives of this study

1. To explore the experiences of family members living with hypertension within a family group
2. To explore the experiences of family members in managing hypertension control
3. To understand the potential facilitators for, and barriers to hypertension management in families.

1.5.2 The study questions

To gain an understanding of families' experiences in hypertension control, in relation to stress, diets, roles and responsibilities, and the characteristic of hypertension, three main research questions were formulated:

1. In what ways do family members experience the impact of an individual living with hypertension within a family group?
2. How do family members experience the management of an individual's hypertension control within the family group?
3. What are the potential facilitators for, and barriers to hypertension management in families?

In summary, the impact of hypertension upon the development of cardiovascular disease and premature deaths is a global issue. However, the burden for low-middle income countries, such as Indonesia, is extreme due to 1) the lack of medical and financial resources, 2) the scale of demographic transitions that is contributing to the increase in the elderly population, whose members are more vulnerable to the development of NCDs including hypertension, 3) urbanisation and globalisation that influence diet transition and 4) the increase of sedentary lifestyles. In addition, the increased prevalence of smoking due to poor or inadequate policies failing to regulate smoking or implementing its cessation, is also associated with the

increase hypertension prevalence in Indonesia. Therefore, Indonesia needs to initiate cost effective interventions to tackle hypertension by encouraging patients' self-management. However, the family as the most important social support system available for individuals inevitably influences the individual's practice of self-management. Therefore, there is a need to ensure that constructive social support is in place in order to facilitate and achieve the family-member-patient's improved self-management. This study aims to explore families' experiences in hypertension control in Denpasar, Bali, Indonesia.

2 Literature Review

2.1 Introduction

In this second chapter I present the literature review which consists of 3 parts. The first part elaborates the search strategies used with the literature. The second part focuses on the research location of Indonesia, and specifically the city of Denpasar, where the study was conducted. The research location section helps to illustrate the place and cultural context of the research, which covers information of the geographical position, population, socio-demographic conditions, and the meaning of health and illness within an Indonesian context. The penultimate part of this review discusses hypertension control, including the definition and classification of hypertension, strategies in hypertension control, and the role of the family in hypertension control.

Chapter II, the literature review section of this thesis, encompasses a range of studies, policies and related theories in order to identify research gaps within the topic of “families’ experiences in hypertension control” and to validate findings presented later in chapter 5. Therefore, a systematic review of studies in hypertension management is not attempted; instead a literature review focusing on key aspects of family experiences in hypertension control was the chosen focus.

In the previous chapter (Chapter I) it was stated that hypertension is still a huge burden for Indonesia’s health system and one that is growing, in part because the control of the condition is still poor. Focusing only on the individual patients is the main method employed to control hypertension. However, in an Indonesian context the family is the closest social support unit available for the patients; it is therefore inevitable family members will be included in attempts at managing a family member’s chronic condition. The purpose of this review is to highlight the importance of social support in hypertension control, as well as the family’s

involvement in hypertension control. Any relevant knowledge gaps will be outlined at the end of the chapter. The following section discusses the search strategies that were used in this literature review in order to identify relevant published materials.

2.2 Search strategies

Relevant literature has been searched through electronic journal databases such as ASSIA, CIHNAL Plus, MedLine, Cochrane Library, Scopus, JStor and Google Scholar. In addition to those electronic databases, the University of Edinburgh's DiscoverEd search engine was also utilised to retrieve related articles. The majority of publications identified were from 2000 to the present. Some publications published before the year 2000 were also included in order to provide theoretical perspectives to the study. Since there is only a limited number published materials available regarding families' experiences in chronic disease management in an Indonesian context, the majority of the information presented in this literature review is from the US, European countries including the UK, and some Asian countries. Both simple and advanced searches were conducted, to retrieve the materials. For the advanced search, key words were combined with AND, OR, and NOT to find the intended materials. In addition to more sophisticated searching strategies, a manual search was also used to retrieve some articles in reference lists of identified literature. Literature research locations included statistical data in the fields of mortality, morbidity and public health policies. They were located through the WHO website and the World Bank, as well as related agencies' websites in Indonesia such as the Ministry of Health, Statistic Indonesia, and the Ministry of National Development Planning. In addition, literature discussing religions and cultures related to health and illness was also searched to provide information about the influence of those issues on ill health within Indonesian society. During the literature search, inclusion and exclusion criteria have been

employed to yield relevant sources. The criteria informing source selection are presented in Table 1.

Table 1: Inclusion and exclusion criteria for literature search

No	KEY QUESTIONS	CRITERIA	
		Inclusion	Exclusion
1	Hypertension prevalence	<ol style="list-style-type: none"> 1. The WHO data globally 2. The WHO data in South East Asia Region 3. Data for hypertension in Indonesia 	<ol style="list-style-type: none"> 1. The WHO European data
2	The underlying factors of hypertension in Indonesia	<ol style="list-style-type: none"> 1. Socio-economic determinants of hypertension 2. Health financing and its policies in Indonesia 3. Smoking behaviour in Indonesia 4. Economic growth in Asia and Indonesia 5. Food trends and hypertension 6. Smoking and food safety policies in Indonesia 	<ol style="list-style-type: none"> 1. Hospital policies in hypertension treatment
3	Hypertension control	<ol style="list-style-type: none"> 1. Anti-hypertension treatment adherence 2. Behavioural change in hypertension control 3. Barriers and facilitators of hypertension control 4. Lifestyle change in blood pressure control 5. Home blood pressure monitoring 	<ol style="list-style-type: none"> 1. Comparison of drugs' effectiveness 2. Blood pressure control during pregnancy 3. Lifestyle modification in children 4. Pharmacology treatment for cancer, diabetes, HIV and pain
4	Social support for a chronic condition	<ol style="list-style-type: none"> 1. Social support for hypertension 2. Social support for lifestyle modification 3. Lifestyle modification and peer supports 4. Family roles in diseases management 5. Family caregiving for chronic conditions in Asian and Indonesian contexts 	<ol style="list-style-type: none"> 1. Social support for cancer, pain and HIV 2. Doctor-patient relationship 3. Healthcare professionals' support
5	Disease management in system family	<ol style="list-style-type: none"> 1. Family system and chronic conditions 2. Family system and health behaviour 3. Family system and hypertension 	<ol style="list-style-type: none"> 1. Tuberculosis treatment management 2. Family caregiving in pulmonary arterial hypertension

The following section is the second part of this literature review that elaborates upon the study location, which is essential to provide a thorough introduction to the readers about Indonesia, and specifically Bali, where the study was conducted.

Presented are details of socio-demographic conditions, the multicultural nature of Indonesia, the Indonesian health system, and the general perceptions of health and illness for Indonesians.

2.3 Research location

This section describes the study location, including 1) details of Indonesia's geographical position, 2) general population, 3) socio-demographic conditions, 4) Indonesia as a multicultural country, 5) the Indonesia's health system, and 6) the family's general perception of health and illness in an Indonesian setting.

Indonesia is a multicultural country with hundreds of ethnic groups, but for this section only 4 ethnic groups are discussed, as they are the majority groups that reside in the study's location. The four ethnic groups discussed in the later section are Javanese, Balinese, Minahasan and Chinese. The Indonesian health care system is then described, including points relating to 1) national coverage, 2) the state health organisations and 3) facilities in Indonesia.

2.3.1 The geographical position of the study location

According to the Geospatial Information Board (2017) Indonesia has 16,056 islands that stretch between the Indian and Pacific oceans. Indonesia shares land borders with Malaysia, Papua New Guinea, and East Timor; nearby countries include Singapore, the Philippines, and Australia. There are 35 provinces in Indonesia; the capital of the nation being Jakarta, a city in the western part of Java island. Bali is an island and a province in Indonesia that is renowned as a destination for international tourists. Bali lies between the Java and Lombok islands, 8 degrees south of the equator. Other than Bali island, five small nearby islands are included in the territory of Bali province: Nusa Penida, Nusa Ceningan, Nusa Lembongan, Serangan island and Menjangan island. The overall area of Bali province is 5,634 km², includes eight regencies and a city. Denpasar is the city and

the capital of Bali province; it is positioned in the southern part of the island, and contains four subdistricts: East, West, North, and South.

2.3.2 Population

Indonesia is the 4th most populous country in the world, with an overall population 237,641,326 in 2010, and is projected to reach 271,066,400 in 2020, comprising of 633 ethnicities (Statistic Indonesia, 2018). Bali's population numbered 3.8 million in 2010, and is projected to reach 4.3 million in 2020, of which 788.589 people live in Denpasar (Statistics Indonesia, 2015, Statistic Indonesia, 2018). Bali is a province in Indonesia that has completed its first demographic transition, where the fertility and mortality rates are high and is now in its second demographic transition, where the fertility and mortality rates are reducing (Ananta et al., 2014). The better health systems in Indonesia have improved life expectancy and shifted the demographic scenario of the country, characterised by a consistent increase in the older population. Bali is ranked fourth in Indonesia as the province with the most number of older adults. With the rapid increase of older people, within the next 20 years the number is projected to more than double (Ministry of Health Republic of Indonesia, 2015). The issues of morbidity and disability increase significantly with age, and hypertension is one of the most common health complaints reported by older people in Indonesia (Ministry of Health Republic of Indonesia, 2015).

2.3.3 Socio-demographic conditions

The following section discusses socio-demographic conditions in Indonesia. I begin by providing an overview of the multicultural background, the religions in Indonesia, followed by descriptions of the socio-cultural contexts of the Balinese, Javanese, Minahasan and Chinese groups involved this study. The participants of this study are mostly Balinese; however, there are two Javanese families, one mixed Javanese and Minahasan family and one Balinese Chinese family. A

discussion about cultural aspects is offered in this section to provide an overview of the differences in the families included in this research.

Indonesia is a multi-ethnic, country with around 633 ethnic groups residing from Sabang (the westernmost city) to Merauke (the easternmost city) (Statistics Indonesia, 2013). Javanese is the largest ethnic group in Indonesia, representing about 40% of the country's total population; whereas the Balinese make up only 1.6% of the total population. The Javanese not only reside in Java but are spread across the country, as well as abroad in other nations (Statistic Indonesia, 2013, Ananta et al., 2014). The Balinese mainly reside in Bali, and also in another province, but the number of 'outliers' is small (Ananta et al., 2014).

Interactions between hundreds of indigenous ethnic groups, combined with the influence of foreign merchants during the ancient trading times and the colonial period, have shaped a multicultural Indonesia (Abdullah, 2009). The religions (Buddhism, Confucianism, Islam and Christianity) that the foreign traders introduced during the ancient trading times have been adapted into the framework of indigenous pantheistic animism (Hobart, 2001, Wiryomartono, 2016). Indonesia is a non-secular country and denies atheism. Religion is an essential aspect of life for Indonesians, and it is the first principle of the state ideology, that Indonesians believe in One God and Only God. The first principle of the state ideology is also embodied in the 1945 Constitution of Republic of Indonesia, article 29, points 1 and 2:

"The state shall be based upon the belief in the One God and Only God"
(point 1)

"The state also guarantees all people the freedom of worship, each according to his/her religion or belief" (point 2)

Referring to article 29 point 2, therefore, the state recognises six official religions and there is no one religion as the state religion. The six religions in Indonesia are Islam, Protestantism, Catholicism, Hinduism, Buddhism, and

Confucianism. The majority of Indonesians (87.2% of total population) are Muslims; the percentages of each religion are presented in the Table 2 below.

Table 2: Religions in Indonesia

No	Religions	Percentage	Population
1	Islam	87.18	207,176,162
2	Protestantism	6.96	16 528 513
3	Catholic	2.91	6 907 873
4	Hinduism	1.69	4 012 116
5	Buddhism	0.72	1 703 254
6	Confucianism	0.005	117 091

Religion is not only an expression of an individual's relationship to their God, but is also the greatest influence on a family's norms and social control; an influence which is embedded in every aspect of Indonesian life (Geertz, 1989, D'Antonio et al., 1982, Muhammad, 2007, Hobart, 2001). Therefore, parents introduce religion to their children at a young age and expect religion to guide their children's lives when they no longer available for their children (Muhammad, 2007). Muhammad (2007) adds that when parents are unable to teach their children the 'correct' knowledge, then they will refer their children to the experts, such as the religion leaders. Commenting on religion in Indonesia, (Geertz, 1973, p.123) notes:

"Religion lies in its capacity to serve, for an individual or for a group, as a source of general, yet distinctive, conceptions of the world, the self, and the relations between them, on the one hand— its model of aspect— and of rooted, no less distinctive "mental" dispositions— its model for aspect— on the other. From these cultural functions flow, in turn, its social and psychological ones."

In Indonesian society, religion and culture cannot be separated; expressions of religion are mostly embodied in culture (Geertz, 1973). Many cultural rituals in Indonesia are an expression of the religion that people belong to, and where worshipping often involves collective communal activities (Geertz, 1973, Muhammad, 2007, Sukmana, 2014). Culture for Indonesians is an identity of their ethnic group, and preserving culture could improve the position of an ethnic group within the multiethnic Indonesian nation (Picard et al., 1997). The family system

introduces individuals to cultures, values and customs that are practiced within society. Through those experiences the adult children gain the understanding, emotional equipment and moral commitment to act as members of their own community, and society in general (Geertz, 1989). In the next section I discuss the cultural context of Javanese, Balinese, Minahasan and Chinese families.

2.3.3.1 Indonesia as a multicultural country

Indonesia as a multicultural country consists of hundreds of ethnic groups, and each has its own distinctiveness; however, there are also commonalities where the majority of the groups adopt similar cultural values. The focus of discussion in this section is about marriage, family, and intergenerational arrangements in Indonesian society; all issues which form a background for further discussion about 'family as a system' in the following chapters. Marriage remains near universal and common in many ethnic groups in Indonesia (Jones, 2005, Astrup et al., 2011). However, even though it remains universal, the numbers of non-married people or delayed marriages is increasing, especially in big cities. One reason suggested for this trend is that many younger people prefer pursuing careers and studies rather than the state of marriage (Jones, 2005). As for the 'before and after' married life, in many ethnic groups it is common for young adults to stay with their parents before marriage, and to remain with them after marriage for a period of time, until the new couple are able to afford to form their own independent households (Williams, 1989, Bittenheim and Nobles, 2009, Williams, 1990).

Intergenerational living arrangements remain common in Indonesian society, even though the model's numbers are declining. It is suggested the decline is because there are more work/life opportunities available in the city, consequently promoting urbanisation (Johar and Maruyama, 2011). In a social context, the cohabitation living arrangements differentiate a collectivistic culture, such as

Indonesia, with individualistic society (Trommsdorff and Schwarz, 2007). Adult children involved in cohabitation living arrangements are considered to be adhering to the traditions in fulfilling their lifelong obligations to their parents, in the form of support and respect nurtured by filial piety (Trommsdorff and Schwarz, 2007, Johar and Maruyama, 2011). In addition to the matter of filial obligation, Buttenheim and Nobles (2009) add that the co-residence with their parents of adult children after marriage, is based on certain considerations. Amongst these are: a) the inheritance of land and property, b) the norms in Indonesian society for child care, and c) the decisions of the timing for childbearing. Land and property inheritance will consider the *adat* laws (local ethnic based laws and customs); each ethnicity has its own arrangements, and these will not be discussed further in this study. Meanwhile, for child care the grandparents will usually look after their grandchildren. Such a duty is seen as a form of investment for the future, based on the expectation they in turn will be taken care of by their children and grandchildren in the years to come (Snopkowski and Sear, 2015, Schröder-Butterfill, 2004).

Economics are not the only reason for Indonesian families to have children, but there are other cultural values underlying the decision to have a child. Society considers to have children is a blessing and contributes to a family's well being (Koentjaraningrat, 1985). Other than that, in more collectivist societies, such as in Indonesia, to have children may improve the quality of married life. Children, especially sons, will ensure the continuity of a family's lineage (Trommsdorff et al., 2002). Being childless in Indonesia is to be considered a failure; the male and female in such a marriage will be perceived as inadequate. A family without children is incomplete, or a 'failed family' (Trommsdorff et al., 2002, Bennett, 2012). In the case a family where, for medical reasons, it is impossible to have children, such as due to infertility, adoption is an alternative; a decision and process that is accepted by dominant religious and cultural institutions and legally supported by the state

(Bennett, 2018). Bennet (2018) adds that, for Indonesian families, adopting intra-familial children is preferred, in order to ensure the continuity of both ethnicity and religion.

For Indonesians, parents place a high expectation on their children that they will be able and willing to provide care for their elderly parents. However, in reality cohabitation living arrangements may not always prove to be a better way of living for the elderly, because they tend to experience negative co-residence effects, such as deterioration in their health status (Johar and Maruyama, 2011). Instead of being supported by their children the elderly parents most of the time become the economic backbone of the family and have to support their children, especially for material needs; a situation referred to in many countries as “the bank of Mum and Dad” (Snopkowski and Sear, 2015, Schröder-Butterfill, 2004).

The aforementioned is a general overview of family arrangements within Indonesian society. However, the daily lives of Indonesians are strongly influenced by their ethnic cultural values. Therefore, the following sections discuss the Javanese, Balinese, Chinese and Minahasan ethnic groups, and their cultural values, as the elements of family life for the ethnic majority in Denpasar.

2.3.3.2 Javanese, Balinese, Minahasan and Chinese cultural backgrounds

2.3.3.2.1 Javanese family

Java is the most populated island in Indonesia; 60% of Indonesian population lives in Java (Statistic Indonesia, 2013). The homeland of the Javanese is in the central and eastern parts of Java island but the Javanese reside across the country and even in other countries (Statistic Indonesia, 2013). Their existence all over the country has also spread Javanese culture throughout the archipelago, and it has influenced the establishment of Indonesian lifestyles, which then established and shaped the national cultural identity (Wiryomartono, 2016). Wiryomartono (2016)

adds that the predominant influence of Javanese culture in Indonesia is also because Javanese people hold many important positions in national, regional and local level governments; so enabling them establish and inform leadership roles administratively and culturally to shape the national cultural identity.

For a Javanese, the family is the most important kinship unit; one which includes the parents, children, and spouses (Geertz, 1989). The Javanese family is the closest network that will provide emotional security, moral guidance, care across the lifespan, and a place where its members can learn and relearn about Javanese culture (Geertz, 1989, Wiryomartono, 2016).

Javanese families always teach their children to be able to manage their feelings and emotion so they can still be *sabar* (patient) and *prihatin* (concerned). The children are also encouraged to do *semedi* (meditation) and *tawekal* (reflection) to survive in any bad situations (Wiryomartono, 2016). Wiryomartono (2016) adds that the Javanese prefer to keep in harmony with their surroundings; therefore, they usually avoid open conflicts and confrontations in solving a problem. As much as possible they try not to be too obvious and self-important. Javanese place great value on maintaining individual relationships, by fostering harmony, co-operation, unity of effort, as well as minimising conflicts called *rukun* (Geertz, 1989). Javanese parents always emphasise the importance of respect; a concept that not only has the meaning of respecting those with superior power: respect in Javanese is a complex value (Geertz, 1989). Also, Geertz (1989, p.114) suggests respect appears when Javanese are feeling afraid (*wedi*), or embarrassed (*isin*); they are also respectfully polite before a superior or an unfamiliar equal (*sungkan*). Geertz concludes Javanese children develop initiative or independence poorly as the result of a suppressive environment created by their parents who demand those children to be obedient, well behaved and quiet; requirements reinforced by Javanese culture. Having children is very important for the Javanese (Geertz, 1989). They

believe it is a process of paying back the debts incurred by ancestors. Childlessness is a terrible thing for a family, because it means

"There is no future, no continuity and it is a complete and irreversible end to a person's existence" (Brenner, 1998,p.186).

Javanese households can be varied in size and composition (Geertz, 1989, Brenner, 1998). However, the structure of a Javanese family challenges the stereotype of an Asian patrilineal joint family; nuclear/bilateral families make up the majority of Javanese households (Kreager and Schröder-Butterfill, 2008, Geertz, 1989). Newlyweds usually live with the wife's family until they are financially and residentially settled. Alternatively they may move after three to five years when they settle into their own place; a home which will be not too far from the wife's family, because parents would prefer the daughters take care of them in their old age (Geertz, 1989, Koentjaraningrat, 1985). Women have a strong position in Javanese society; they control the family finances and make most of the decisions for their family, although for some major family issues the wife will still consult her husband (Geertz, 1989). There is an obligation that the husband gives most, or all, of his money to the wife so that she can use it for the household expenditure; the husband will only receive 'pocket money' (Brenner, 1998). Not only do Javanese women have strong power inside the house, but they are known for running better businesses and trading better than the men (Brenner, 1998, Geertz, 1989). Newberry (2006) suggests women in Javanese society are also the implementers of moral control, who will watch another's behaviour and take action when it is necessary. Interestingly, however it is their men who will be required to act upon their wives' judgement. As Brenner notes, men in Javanese society are the ones who deal with the outside world, particularly formal state bureaucracy; at home they just act as the head figure in the family (Brenner, 1998). As mentioned earlier that daughters will keep a close relationship with their parents after their own marriage.

This relationship benefits the women because if they experience a hard time, such as a divorce, they can return home and live with the parents; a transition that rarely happens to the men (Geertz, 1989). Men probably appear to be the head of the family from external society's point of view, but women are the ones who control the family and have the power in the daily lives of Javanese families and society.

Javanese are the major ethnic group in Indonesia. In the next section I discuss the cultural context of the Balinese family, as the ethnic majority in Bali.

2.3.3.2.2 Balinese family

Balinese culture has been shaped by strong Javanese, Indian and Chinese influences (Hobart, 2001). The Hindu in Bali form a mixture of indigenous religions from the Pre-Hindu time, Buddhism from India, and Siwaist-Buddhism, the religion from the Majapahit empire in East Java (Hobart, 2001, Geertz, 1975). Bali is the only place in Indonesia that preserved the great Indonesian Hindu civilisation (Pringle, 2004). Balinese society is a complex interplay of culture and religion that is very confusing. As Geertz (1975, p.12) says

"The entire social structure is suffused with religious concern, and almost every kind of social relationship, from the most collective to the most personal, is either necessitated by or validated by ritual".

Marriage is a must for Balinese Hindus, so the children can be born to continue the patrilineal line. When a Balinese woman marries a Balinese man, she will leave her family's house and join her husband's family. The Balinese worship their ancestors in the family or clan temple and so, upon marriage, a woman not only leaves her family but also her ancestors, to join and worship her husband's ancestors. The newlyweds inherit all the social and religious obligations of the husband's parents. Socio-cultural institutions in Bali are very important for Balinese life, because they are tied to certain institutions, such as: i) *desa pakraman* (customary village), ii) *subak* (rice-farmers' organisation), iii) *subak abian* (upland

farmers' organisation) and iv) *pemaksan* (temple congregation) (Pitana, 2010). Pitana (2010) suggests that these institutions are traps for the Balinese as they regulate what they should do and not do in their daily lives. Balinese follow a local wisdom concept called *Tri Hita Karana* (three causes of happiness); to achieve happiness humans need to maintain harmonious relationships with i) God, ii) the natural environment and iii) other human beings. Religion is an important vehicle to maintain harmonious relationship with God. The majority of Balinese are Hindu believers, and it is impossible to separate their daily lives from their religious concepts and ceremonies; the activities of those two components being concentrated on specific temples (Hobart, 2001). Balinese spend a lot of their time taking part in ceremonies, which are frequent, involving many carefully arranged parts or details and requiring lengthy preparations (Geertz, 1975).

Men and women have specific duties during the ceremonies. Men's main duties include preparing foods that is mostly made of meat and all the installations that are needed for the ceremonies. The most important duty for women is preparing the offerings that are needed during the ceremonies. Offerings or *banten* are a creative expression to thank their God and all his manifestations for the blessings that have been given to the people (Hobart, 2001). Other than as an expression of gratitude, *banten* is also a vehicle to calm the demons (*buta*) that are believed to be able to disrupt people's well-being. The main ingredients of *banten* include fruits, cakes, flowers and intricate palm leaf decorations. The size of offerings depends on the scale of the ceremony. In a large ceremony, such as a temple anniversary, the women who are members of the temple will produce the offerings together in the temple complex; an activity called *ngayah*. They usually spend several days for *ngayah*, working from morning to afternoon prior to the big day, in order to produce the offerings.

A Balinese family can be associated with more than one temple, so they are obliged to *ngayah* in each temple during its anniversary. Conflicts can emerge when they have to *ngayah* during the weekdays or if it takes many days before the big day; such obligations mean they must leave their job or the household duties for a while. Usually, adult women in a family can attend the *ngayah* in turn, with at least one of the female family members from a household present during the making of offerings. This female representative will be the mother, a single adult daughter, or a daughter in law. This situation would be even more burdening for the family if there is only one female member in the household, because it means she then needs to attend to all the activities by herself, because that is her obligation as a member of the temple. *Metulungan* or providing mutual assistance among all members of the village, in the human-life-circle ceremony, is a form of maintaining a relationship with other human beings (Rivai, 1981, p.139).

Domestic tasks remain predominantly the women's responsibility in Balinese society, which obliges them to spend most of their time on those tasks, thereby creating tremendous stress and leading to health deterioration, including cases of hypertension (Doyal, 1995). Geertz (1975) describes a ceremony as a very complicated event that requires attention to many detailed parts, ensuring that the making of offerings is one of a Balinese woman's everyday activities. They will make and gather the parts little by little in their spare time. The Balinese women carry too great a burden on their shoulders. Not only do they have their responsibilities for dealing with the household chores, they also have to fulfil their social obligations at the temples, by helping their kin with the religious ceremonies and the many others social gatherings and activities.

Bali is a province in the eastern part of Indonesia. Its flourishing tourism industry attracts other ethnic groups from neighbouring islands to work and stay in

Bali. One of the ethnic groups that is commonly found in Bali is the Minahasan group, which is discussed in the following section.

2.3.3.2.3 Minahasan family

The Minahasans are an ethnic group located in North Sulawesi province, in the eastern part of Indonesia. They are the biggest ethnic group in North Sulawesi, and they are also called the Manado people. The North Sulawesi province, unlike most other regions in Indonesia in which Islam is dominant, is a Christian-majority region, with the Christian population in this region being at the 60% level (Statistics Indonesia, 2014). Christianity was introduced by the Europeans (Portuguese, Spanish and Dutch) in 1500 and was then actively spread by the Dutch Missionary Society during the Dutch colonial period (Kim, 2017, Jacobsen, 2002, Maleke, 2013). Therefore, Christian values have predominantly informed the Minahasans' socio-cultural values, beliefs and behaviour (Kim, 2017).

The strong Christian influence of the Dutch during their colonisation of Indonesia gave the Minahasans' culture a bias towards a more western way of life, causing the alienation of Minahasans from their pre-colonial cultures and traditions (Jacobsen, 2002). The fascinating fact about the Minahasan is that they have been strongly influenced by Christianity, and a patriarchal notion was strongly encouraged within the community. However, the pre-colonial Minahasans' cultural values that considered the status of men and women as complementary, rather than hierarchical, are at times still in evidence (Ye-Kyoum, 2015). Ye-Kyoum (2015) mentions that the consideration of equality was not necessarily fully practiced, because egalitarianism was never entirely adopted in Minahasa, especially during the new order regime in the 1960s. At that time, half a century ago, the ideology of *ibuism* (womanhood) emphasised women's roles in the domestic domain. In terms of the dominant influence over decision making, there are three types of negotiation

that are usually used by Minahasan couples. The three types are: i) male-dominated negotiations, ii) female-dominated negotiations and iii) alternative negotiations, with both male and female are equal agents. Such a negotiation model tends to differentiate the Minahasan from other ethnic groups in Indonesia (Kim, 2017).

In addition to native ethnic groups, Indonesian populations are also made up of people from Chinese backgrounds. The settlement of Chinese all over Indonesia has added another ethnic group to the country population. Further discussion of the Chinese in Bali is discussed in the following section.

2.3.3.2.4 Chinese family in Bali

The Chinese have been a strong minority in Bali; their settlements on the island extend far back before the colonial period (Salmon and Sidharta, 2000, Gottowik, 2010). However, the particular period when the Chinese first started migrating to Bali remains poorly documented. The latest documentation, was found in a temple in 1999; the temple itself is a place to worship the deities of the Hainanase dating back to 1888 in southern Bali (Salmon and Sidharta, 2000). Balinese culture has been strongly influenced by the Chinese, including aspects of religion, cuisines, art, and economics (Gottowik, 2010). The Chinese integration into Balinese society was started through trade and marriages to locals that finally made the Chinese settle in Bali (Gottowik, 2010, Salmon and Sidharta, 2000, Tan, 1991). Of the Chinese families who reside in Bali, the majority are third or fourth generation, and so they are called Chinese Balinese (*Cina Bali*). The Chinese traditions are not very important anymore for the Indonesian Chinese younger generations, although some rituals are still preserved and celebrated.

The expression of the traditions that are evident today include the Chinese New Year and eating Chinese food (Koning, 2007). Meanwhile the majority of Balinese Chinese, who still practice the traditions, do so in addition to Balinese and

Hindu cultural rituals, as a result of acculturation between Balinese and Chinese ethnicity (Gottowik, 2010, Aryana, 2017). In every traditional Chinese celebration, food is the vital component as an expression and establishment of relationships between people and their environment; as well as between people and what they believe (Ma, 2015). Ma (2015) pointed out that the preparation of foods in a Chinese family traditionally as seen as one of the women's responsibilities, in addition to other household tasks. The Chinese men are held responsible for dealing with external affairs and work. However, it should be noted that in contemporary Chinese society these traditional roles have slightly changed, due to women also joining the work force; (Jacka, 2013). Chinese kinship, similar to much of the world, traditionally follows the patrilineal and patriarchy model. A married woman leaves her parents' house and move to live with her husband's family (patrilocal). The kinship patterns for Chinese Balinese predominantly follow the same rule.

2.3.3.2.5 Summary

Each ethnic group has its own unique attributes. The four groups mentioned above are just a small sample of the many ethnic groups which exist in Indonesia. In each group the family ties, kinship, religion and cultural practices are essential to their daily lives. Cultural elaboration will provide an insight into the backgrounds of the families that participated in this study.

Indonesia, as a country with a very diverse population, is experiencing a series of demographic, epidemiological, social, economic and political transitions. Also being experienced are transitions in the healthcare system to ensure the delivery of health services meets the health needs of the entire population. The following section is an elaboration of Indonesia's healthcare system.

2.3.4 Indonesia's healthcare system

The transition of demographics in Indonesia has influenced the epidemiological change in which levels of non-communicable diseases (NCDs) have increased significantly, while the communicable diseases still remain a burden for the country. With this double burden of diseases, Indonesia's health services have not been well prepared for this challenge, due to insufficient facilities and workforce personnel to cover all geographic areas. Before a discussion of the healthcare system in Indonesia, I present a brief description of the political situation that leads reformations in all public sectors, including health care. I will then discuss the healthcare services in the following sections.

2.3.4.1 Political situation's impact on Universal Healthcare Coverage

In 1998, following the resignation of Suharto, the second president of Indonesia, who was in power for 32 years, Indonesia experienced various social reforms. The most important change that significantly affected the health care system was a switch of government authority from a powerful, centralised, autocratic model, to decentralised rule. The parliament passed decentralisation laws in 1999, which allowed power to be devolved to the second tier-district (Kabupaten/Kota) level, instead of the first, province level. Following the massive political changes, Indonesia was hit by a severe financial crisis which caused a struggle in financing health care, especially for the poor. Many expected and hoped decentralisation could improve efficiency and eliminate corrupt central bureaucrats, so that people would receive better public services. However, due to a lack of both effective coordination and competent administrators, many local governments perceived they must generate as much income as possible, leading to healthcare services being increasingly privatised; thereby causing broader health inequities. The reality was that some people could pay, but others could not (Kristiansen and

Santoso, Thabrany, 2008). As for the healthcare financing, in 1992 the government passed the Indonesian Security Law (Law no 3/1992) which regulated the nation's social security schemes, including healthcare benefits. During this period only 10% of all Indonesian (both workers and their families) had healthcare coverage; those who had cover were private sector workers in the formal sector, civil servants and their families, as well as retired civil servants (Arifianto, 2004).

However, Arifianto (2004) notes that the schemes did not cover the vast majority of Indonesians who worked in informal sectors, such as daily workers, self-employed individuals, employed and formal sector workers who were employed by small businesses with ten employees or less. They must cover their healthcare expenses out of whatever they earned. As a result, access to health care remained highly unequal. Due to the limitation of the schemes, and to reduce the health inequities resulting from the financial crisis, in 2004 the government finally passed a National Social Security System Law (Law no 40, 2004) (President Law, 2004). The law regulates the implementation of the social security system for all Indonesians; the goal is for all citizens to receive comprehensive social protection. Indonesia has proposed multiple health insurance programmes since the law passed on the 19th of October, 2004. In the beginning, health insurance was only for employees in the formal and informal sectors, and there were several insurance programmes for different types of employees. In 2005 the government created another insurance programme especially for the poor, followed by another insurance programme to reduce levels of maternal and child mortality in 2010. However, these various schemes could not give comprehensive protection for all citizens, because the medical services coverage is limited, and the services are of poor quality (Asian Development Bank, 2010). The government finally set a goal to achieve Universal Health Coverage (UHC) by 2019. Therefore, the National Social Health Insurance Scheme or *Jaminan Kesehatan Nasional* (JKN) was launched in January 2014. The

JKN was created as a consolidation of multiple insurance programmes that covered the employees (both formal and informal), the poor and pensioners, under one national administrative, management, service system; while at the same time evaluating the programme for improvements (Mboi, 2015).

The JKN is the latest of Indonesia's national health insurance initiatives, and *Badan Penyelenggara Jaminan Sosial* (BPJS) or the Social Insurance Administration Organisation, is the newly-formed organisation that administers the programme (BPJS, 2017). The members of this insurance are all citizens, including expats who have worked in Indonesia for a minimum six months. The two types of membership are: 1) state subsidised participants, for the poor (they are called PBI) and 2) non-PBI, including all employees, self-employed, non-formal workers. The new health insurance scheme is expected to cover all citizens by 2019, but to date (March, 2018), the insurance has covered only 190 million of the 250 million population (BPJS, 2017). Participants keep complaining about its poor quality services, inexperienced providers and lack of evaluation for improvement, to name just three issues that are challenging the success of this ambitious plan (Pisani et al., 2017).

2.3.4.2 Health organisation and facilities in Indonesia

Many changes in healthcare services followed the decentralisation of government in 1999. The Ministry of Health (MoH) and Ministry of Home Affairs took on the primary responsibility for healthcare services in Indonesia. The provincial and district governments that are under the Ministry of Home Affairs, now have the responsibility for planning and managing the healthcare services. Meanwhile, the central Ministry of Health retained its responsibility for tertiary and specialist hospitals. The Ministry of Health mainly takes the role in creating regulations,

providing resources, managing and planning issues in public health, and ensuring the national health insurance covers all of Indonesia's citizens (Mboi, 2015).

2.3.4.3 Health facilities in Indonesia

Both public and private sectors organise healthcare services in Indonesia. Residents who have registered for the JKN, can access all the health facilities that join the BPJS, including the first level health facilities and advanced health facilities (Ministry of Health Republic of Indonesia, 2012).

Health facilities in Indonesia are organised in a tier system. Non-emergency patients can access the primary care health facilities without a prior appointment, but when they need to access hospitals or more specific care they need a referral letter from the primary care facilities. The healthcare services at primary level are delivered by the public sector via community health centres (*Puskesmas*). Services from the private sector come via private clinics, and the private practices of non-specialist health care providers (GPs, nurses, and midwives). For emergencies, patients can get access to treatment at a general hospital through its emergency unit. For inpatient facilities, the public sector provides *Puskesmas* with inpatient wards, and there are also provincial and district hospitals. The private sectors also organise inpatient facilities that JKN members can access. The discussion of *Puskesmas* and chronic diseases management will be presented in the following section.

2.3.4.3.1 *Puskesmas* (Community Health Centres) and PROLANIS

I am focusing this part on addressing *Puskesmas*, from where I recruited all of my research participants. *Puskesmas* or community health centres are health facilities delivering first level healthcare services for communities and individuals. Their primary role is to promote health and prevent diseases, by achieving and

maintaining the highest level of health within their coverage area (Ministry of Health Republic of Indonesia, 2014).

There were 9,825 *Puskesmas* in Indonesia in 2017; of which 3,459 provided inpatient care as well as all 9,825 offering outpatient care (Ministry of Health Republic of Indonesia, 2017). Bali has 120 *Puskesmas*, and 11 of those are located in Denpasar, which is where I conducted my study. *Puskesmas* is a sub-district health centre that serves a population of 30,000. There are two types of *Puskesmas* categorised by their ability at delivering health services: those 'with beds' and those without beds or 'non-beds'. The non-bed centres are for outpatient care only; those clinics with beds provide both outpatient and inpatient care. The essential health care services covered by *Puskesmas* include: a) health promotion, b) environmental health services, c) mother, child and family planning services, d) nutrition services, and e) disease prevention and control services.

The *Puskesmas* are staffed with medical practitioners, dentists, nurses, midwives, community health staff, environmental health staff, lab analysts, nutritionists, and pharmacists. *Puskesmas*, as the front line in providing care and preventing diseases in individuals and communities, play a significant role in controlling non-communicable diseases. *Puskesmas*, in collaboration with BPJS, adopted an integrated programme for chronic disease management, called PROLANIS. PROLANIS stands for *Program Pengelolaan Penyakit Kronis* (chronic diseases management programme). It is a programme developed by BPJS in 2010, which was later adopted by the government to implement chronic disease management at the primary level. PROLANIS is a proactive approach to maintaining the health of those BPJS members with chronic illnesses, especially hypertension and type-2 diabetes. The PROLANIS goal is to achieve the highest quality of life for the most efficient cost (BPJS, 2014). Health services conducted within PROLANIS include: i) health consultation and education, ii) home visits, as a

reminder for the members to visit health facilities regularly, iii) club activities which are mostly for regular exercise and iv) health status monitoring, including the provision of prescribed medications.

PROLANIS enables health staff to monitor their patients' blood pressure and, for type-2 diabetic patients, their blood sugar levels so adjustments to treatment can be made to fit the patients' conditions (Sinuraya et al., 2017). Other than regular monitoring, patients also gain support from their peers, share information and feel healthier; all of which serves to increase their motivation to control and manage their disease (Rahmawati and Bajorek, 2015). However, the patients' continuity in following the programme may not be ideal, because of those patients' other activities and commitments. Such conflicting priorities meant patients were not always able to attend the regular events planned by the *Puskesmas* (Sinuraya et al., 2017). Other than that, inconsistent attendance to the clinic also challenged, and is still challenging, the success of chronic disease management. The reasons for attendance inconsistency are mostly due to lack of resources, such as medication and healthcare facilities, that reduce the patients' motivation levels to attend (Rahmawati and Bajorek, 2015).

2.3.4.4 Family involvement to achieve 'Healthy Indonesia'

In 2016 the Indonesian government, through the Ministry of Health, issued Regulation 39, which covers the implementation of the 'Healthy Indonesia Programme through a family approach (Ministry of Health Republic of Indonesia, 2016a). The latest regulation aims first of all to increase the family's access to comprehensive health services, including the health promotion and prevention branches, as well as the basic curative and rehabilitation services. Secondly the programme aims to support the achievement of minimal standards of city /regency services by increasing ease of access and numbers of health screenings. This

programme also aims to improve the implementation of national health coverage by improving people's awareness of the services available to them. Lastly, it aims to support the achievement of Healthy Indonesia's goals based on the Ministry of Health's strategic planning 2015-2019. Regulation 39 was issued after this study was conducted; it is being gradually implemented, but has yet to reach all the provinces in Indonesia. There are four priority areas in the regulation: 1) to reduce the death of mothers and infants, 2) to decrease the prevalence of stunting cases, 3) to implement countermeasures against communicable diseases and 4) to reduce and manage non-communicable diseases. The new regulation sets 12 indicators for family health status. There are two indicators relevant for hypertension control: i) the patient is taking medication regularly, and ii) there is no smoker in the family. The main focus of hypertension management is on medication; therefore other healthy lifestyle dimensions, apart from smoking, have been ignored.

The implementation of the guidelines is focused in *Puskesmas*, and it contains very ambitious interventions, including 1) regular home visiting, 2) providing information packages for the family related to the disease management, 3) communication platforms such as focused group discussions, 4) counselling, and 5) various community meetings. This new programme is actually an expansion of the previous programme, but it is designed to be more comprehensive. However, the initiative has several serious shortcomings: 1) the lack of an adequate budget, 2) inadequate human resources, 3) lack of support from local authorities, 4) the need to improve the electronic facilities, 5) lack of knowledge from the community about the programme and 6) inconsistent coordination from the central authority (Laelasari et al., 2017, IAKMI, 2017). Massive changes need to be achieved to improve the programme. For hypertension, the family indicator of controlling the hypertension is only 'taking the medication regularly'; meanwhile there could be several conditions within the family that might affect the quality of hypertension management.

Moreover when the patients are elderly, there are very few formal provisions allocated for them, especially in terms of financial support. Consequently the family has a dominant role to play in providing support and in influencing the decision making of its old age members (Schröder-Butterfill, 2004, Asher, 2002, Hugo, 2002, Ramesh, 2000).

The following section elaborates Indonesians' perceptions of health and illness. Knowledge about these perceptions will enable the readers to understand the ideas of support available in improving health.

2.3.5 Health and illness for Indonesians

“Any definition of health as the absence of self-perceived illness has to deal with the fact that this perception varies widely among individuals and depends on the situation” (Blaxter, 2010,p. 6).

In Indonesia, the definition of health is diverse. The definition of health is strongly affiliated with the religious and cultural backgrounds of Indonesians (Rosales et al., 2017, Subandi and Good, 2018, Dewi et al., 2010, Jennaway, 2003, Indrayana et al., 2019). For most Indonesians, health is a condition needed in order to accomplish daily activities (Dewi et al., 2010). This definition of health aligns with Blaxter's (2010) definition that *health is function*. Someone is categorised as healthy if she/he able to do things; concern is more about their physical ability to do things, with less concern about how they are feeling (Blaxter, 2010). The way Indonesians define health has been associated with their poor performance in preventing disease, because they will not take any action related to their health condition if their daily activities have not been hampered (Dewi et al., 2010). Dewi et al (2010) add that Indonesians' perceptions of health predominantly cause them to delay seeking care. The majority of Indonesians only seek medical help when their illness reaches an advanced stage, resulting in prolonged treatment, more costly treatment or even ineffective treatment (Dewi et al., 2010, Fles et al., 2017, Rintiswati et al., 2009).

Moreover, for most Indonesians health is granted by God, whilst illness is a test from God because the individual has failed to follow the prescribed religion principles (Indrayana et al., 2019). Health and illness are also associated with the maintenance of balance and harmony (Dewi et al., 2010). Javanese society mostly believes that when balance and harmony are missing at individual, family or community level, that condition leads to illness (Dewi et al., 2010). Similarly with the Balinese, the concept *Tri Hita Karana* is a principle that requires them to always maintain harmony between humans, the environment and God to achieve physical and spiritual well being (Suarmini, 2011, Roth and Sedana, 2015, Pitana, 2010). In relation to balance and harmony, in some parts of Indonesia the people also believe in spirits that are ubiquitous. The spirits' roles include watching over the welfare of the house and its inhabitants, and monitoring their behaviour (Wessing, 2010). Wessing (2006) suggests people's misbehaviour can trigger the spirits anger, which may result in punishments, including illness.

Strong belief in invisible power, such as God's punishment and the spirits' anger, is strengthened by poor and/or expensive health services, in addition to the patient having little knowledge about their illness (Rintiswati et al., 2009). This condition of ignorance then leads them to choose alternative or traditional healers, known as *dukun*, or at least to choose *dukun* as the first service they contact before orthodox medical practices (Rintiswati et al., 2009, Fles et al., 2017, Wessing, 2010). They prefer *dukun* because there is no set fee, and the *dukun* is able to give explanations that are related to the patients' experiences. A physician, on the other hand, will almost certainly use medical terminology to explain their patient's case; a process the patient is likely to find extremely hard to understand (Wessing, 2010).

Religion and cultural aspects strongly influence the Indonesians in defining health, illness and health care, and most of the time are more trusted compared to Western medicine, but on the other hand those aspects at some point help to

improve Western-based treatment among Indonesians. For example, Muslims believe health to be the greatest blessing granted by God; thus health has to be maintained, and failing to maintain one's health indicates a personal failure to follow Islam's principles (Rassool, 2015, Padela et al., 2015). Therefore, improving health for chronically ill patients is a part of following religious principles; a very positive aspect of the Islamic religion, as well as others, is to promote health (Indrayana et al., 2019).

2.3.6 Summary

Indonesia is an archipelagic country spread between the Indian and Pacific oceans. The country is divided into three different time zones; it is a multicultural nation, and the 4th most populous country in the world. With all those advantages Indonesia is actually quite a prosperous country, but the characteristics cited above can also constitute a serious challenge for the country and its government. In health, Indonesia is still burdened by communicable diseases, new emerging diseases and climate change; all issues relating to the nation's geographical position. In addition to communicable diseases, the country's profile for non-communicable diseases shows a significant increase, predominantly influenced by a demographic trend which shows an increase in the elderly population. This double burden, however, is not supported by improved health care services. The new universal coverage for healthcare financing is still searching for an optimal pragmatic model that fits the people's needs; one which can do away with the present patchy and inconsistent nature of healthcare services. As a country rich in culture, the daily lives of Indonesians are strongly influenced by their religious and cultural values, in accordance with each individual's ethnic background. Moreover, in health and illness, strong beliefs about balance, harmony, God' punishment, and invisible

spirits that may cause illness have significantly affected disease management among Indonesians.

The third section of this chapter reviews the complex issue of hypertension control and all the interventions related to that issue, and is presented in the following section.

2.4 Hypertension control

Non-communicable diseases (NCDs) are the number one killer (71% or equivalent to 41 million people) of all deaths globally (WHO, 2018b). Based on the WHO (2018b) report, four NCDs as the leading cause of global death annually are: 1) cardiovascular disease (CVD) accounting for 17.9 million, 2) cancer (9 million), 3) respiratory diseases (3.9 million) and 4) diabetes (1.6 million). There are no boundaries recognised by the NCDs, because everybody/anybody may develop one or more of the diseases, thus their prevalence worldwide is rapidly increasing. Hypertension is the leading preventable risk factor for NCDs, especially for cardiovascular and kidney diseases (Mills et al., 2016). Even modest magnitudes in blood pressure reductions are predicted to impact on CVD preventions, both for non-hypertensive and hypertensive individuals (Hardy et al., 2015, Cook et al., 1995, Erlinger et al., 2003). A published result from the Framingham Heart Study shows that a 2 mmHg reduction in diastolic blood pressure (DBP) in the white population would help to reduce the prevalence of hypertension by 17%, as well as reducing coronary heart disease (CHD) by 6% (Mahmood et al., 2014). In addition, risk of stroke and transient ischemic attack (TIAs) would go down by 15%. A study by Hardy et al. (2015) suggested a 1 mmHg decrement in systolic blood pressure (SBP) is associated with reductions of CHD, stroke, heart failure (HF) for both white and African Americans groups. Thus, controlling hypertension to maintain the SBP and DBP in a normal range is required and encouraged to provide effective CVD

prevention. An explanation about hypertension control is discussed further, but in order to provide understanding about hypertension, a section of hypertension definitions and classifications, is presented.

2.4.1 Definitions, classifications and symptoms of hypertension

Hypertension or high blood pressure (BP) is a condition characterised by persistently high blood pressure. Normal blood pressure is a systolic (SBP) pressure of <120 mmHg and a diastolic pressure (DBP) of <80 mmHg in the systemic arteries (Yamout and Bakris, 2017, Oparil et al., 2018). The blood pressure is the result of the blood pushing the walls of the blood vessels every time the heart beats. The normal pressure range is when the pressure as the result of a heart beat (systolic pressure) is less than 120 millimetres mercury, also written as mm Hg. Normality for diastolic pressure, when the heart is resting between beats, is less than 80mmHg (Acelajado et al., 2013, Bakris et al., 2018a). The blood pressure range and hypertension is classified as follows (Yamout and Bakris, 2017, Torpy et al., 2010, Schiffrin et al., 2013):

1. *Normal blood pressure*: SBP <120 mm Hg and DBP <80 mm Hg
2. *Prehypertension*: SBP range 120 – 139 mmHg or DBP of 80 – 89 mmHg
3. *Stage 1 hypertension*: an elevation in either SBP 149 – 159 mmHg or DBP of 90 – 99 mmHg
4. *Stage 2 hypertension*: an elevation in either SBP of ≥160 mmHg or DBP of ≥ 100 mmHg

Another classification of hypertension is based on the cause, which is divided into: 1) essential / primary hypertension, and secondary hypertension. Primary or essential hypertension is a rise in blood pressure of unknown cause. This phenomenon has been related to cardiovascular risk factors, especially genetic factors and environmental lifestyle-related factors, or interactions of these factors

(Kokubo et al., 2015, Cormick et al., 2015). Secondary hypertension is defined as an elevation of blood pressure due to an identifiable cause (Rimoldi et al., 2014, Börgel et al., 2010, Bravo, 2007, Sinclair et al., 1987, Mancia et al., 2013). Primary hypertension is more prevalent, accounting for 90% - 95% of adult cases, whereas secondary hypertension accounts for 2% -10% of cases (Carretero and Oparil, 2000). The five most common causes of secondary hypertension are: 1) obstructive sleep apnoea, 2) renal parenchymal disease, 3) renal artery stenosis, 4) primary aldosterone, and 5) thyroid disease (Rimoldi et al., 2014).

Essential hypertension is almost invariably symptomless, and it is often only incidentally detected because of routine screening or opportunistic measurement of blood pressure (Williams et al., 2015). This type of hypertension is called a 'silent killer' because the majority of sufferers do not know they have it, even though their blood pressure levels are high (Bell et al., 2015). Bell et al. (2015) adds that some symptoms might be experienced by patients when their blood pressure reaches a life-threatening stage. Indicative signs include: 1) dull headaches, 2) vomiting, 3) dizzy spells, and 4) more frequent nosebleeds. Even though patients have been identified with hypertension, it is frequently perceived as an intermittent symptomatic condition, instead of a chronic asymptomatic condition needing long term control (Meyer et al., 1985, Sharkness and Snow, 1992, Ognja and Burnier, 2018). Patients' perceptions of hypertension as being not of a disease but only a 'simple anomaly' have been related to the increase prevalence of heart disease and stroke due to the lack of adherence of such patients taking their medication (Reach et al., 2015, Ognja and Burnier, 2018).

The goal of hypertension management is to control SBP < 140 mmHg, and DBP <90 mmHg for all treated individuals aged <60, and 150/90 mmHg for all those aged ≥60. In addition, other risk factors for CVDs need to be managed, especially: 1) lipid disorders, 2) diabetes, 3) obesity, and 4) smoking (Weber et al., 2014,

James et al., 2014, Mancia et al., 2013). Further details of the strategies employed in hypertension control are presented in the section below.

2.4.2 Strategies in hypertension control

Lifestyle modification and pharmacological therapy are two strategies widely used to address hypertension (Mancia et al., 2013, WHO, 2013, Chung et al., 2018, Cornwell and Waite, 2012, Falaschetti et al., 2009, Kjeldsen et al., 2014, Kotseva et al., 2009, Wolf-Maier et al., 2004, Mendis et al., 2010). Lifestyle modification should be initiated for all patients identified with hypertension (Kokubo et al., 2015). It can be a primary strategy for those with hypertension at no more than stage 1, but medication should be started soon if the hypertension is not responding to lifestyle modification (Weber et al., 2014). Pharmacological therapy is a strategy using anti-hypertensive drugs to lower BP. Examples of the drugs used include: 1) diuretics, 2) beta-blockers, 3) angiotensin-receptor blockers, 4) calcium antagonist, and 5) ACE inhibitors (Mancia et al., 2013). The following sections explain these two strategies, in addition to the barriers inhibiting the implementation of both the pharmacological and non-pharmacological therapies.

2.4.2.1 Lifestyle modification

Hypertension has been associated with lifestyle choices such as: 1) a sedentary lifestyle that leads to a lack of exercise, (2) obesity , 3) smoking, 4) excessive alcohol consumption, 5) rich salty and fatty diets, and 6) stress (August, 2013, Backer et al., 2013, Chen et al., 2013, Demaio et al., 2013, Ferguson et al., 2010, Kavishe et al., 2015). Various lifestyle modification measures have produced significant results in reducing blood pressure (Appel, 2003, Laws et al., 2013, Pongwecharak and Treeranurat, 2011, Svetkey et al., 2009, Eysenbach et al., 2008, Leiter et al., 1999). Lifestyle modifications that are widely known to be effective include: 1) dietary modification, 2) regular exercise programmes and 3) weight loss

intervention. All three initiatives have yielded significant results in reducing blood pressure levels (Farinatti et al., 2016, Herrod et al., 2018, Bacon et al., 2004, Fraser et al., 2014, Yokoyama et al., 2014). In a diet modification programme, black African Americans on vegan diets lowered their SBPs by 1.3 mmHg and their DBPs by 0.6 mmHg compared to those on omnivorous diets (Fraser et al., 2014). Regular exercise for 3 months among older adults helped reduce their SBPs by 5 mmHg and their DBPs by 3 mmHg (Herrod et al., 2018). If the exercise was continued to a long-term, 6 month session, their BPs remaining stable at lower levels thereafter (Farinatti et al., 2016)

Furthermore, it should be pointed out that all of those initiatives have shown positive results in reducing blood pressure that were as effective as anti-hypertensive drugs (Appel et al., 1997, Li et al., 2014b, Moran et al., 2004, Svetkey Lp and et al., 1999, Miller et al., 2002). Lifestyle programmes such as: 1) reducing weight, 2) adding more fruit and vegetables to daily diets, 3) taking regular exercise, 4) quitting smoking, 5) reducing alcohol consumption and 6) developing stress management skills and strategies, have all been recommended for use against stage 1 hypertension. These lifestyle modifications have also been used with later stage hypertension, as a complementary strategy operating in tandem with anti-hypertension drugs.

However, implementation in real life of all, or even some, of the suggested options might be difficult to achieve, because the barriers to hypertension control exist at the healthcare system, health care provider and patient levels (Mills et al., 2014, Fau et al., 2013, Cole et al., 2013, Flynn et al., 2013). Mills et al. (2014) noted there are more barriers at the individual level than in the other two levels. There are 7 barriers that were identified at the individual level, with 4 at the healthcare system level and 3 at the healthcare provider level. Thus, there are more issues that need to be focused on at the individual level and which seem more complicated than in

the other two levels. The individual barriers include internal ones coming from the individuals themselves, such as poor memory and poor motivation (Mills et al. 2014). Additionally there are also barriers emerging from patients' socio- economic cultural backgrounds (Nayeri et al., 2015, Kandula et al., 2015, Quiñones et al., 2015, Murphy et al., 2016). Studies have shown that complex social contexts could present significant obstacles to lifestyle-change implementations (Bokhour et al., 2012, Passey et al., 2014).

Bokhour and colleagues (2012) conducted a study which showed single patients prefer dining out, which is probably a less healthy option than home-made meals. It was also noted that many patients were unwilling, or were effectively unable, to exercise regularly because of the unsafe environments for such activities that existed in their communities (Bokhour et al., 2012). Meanwhile Passey et al. (2014) observed that jobs involving long working hours have also led to failure in adopting healthy eating habits and doing physical exercise, because there are not many choices regarding access and time available for the patients, or that such patients may be just too tired to bother.

Lifestyle modifications showing reduction in BP, the interventions were often overlooked. The mainstay of hypertensive management is pharmacotherapy, because medication is perceived by both patients and medical professionals as more sustainable (Wexler and Aukerman, 2006, Watson and Jamerson, 2003). The following section discusses further the pharmacological therapy in hypertension management.

2.4.2.2 Pharmacological therapy

Anti-hypertensive medications are needed when the lifestyle modifications cannot adequately bring BP down to the required level. In section 2.3.2 it was stated that the classes of anti-hypertension drugs were equally effective in lowering BP,

with 30% to 50% of patients responding well to those medications (Mann, 2015). Patients who were not treated and had not controlled their hypertension with antihypertensive medications have high risks from all causes of CVD, heart disease and cerebrovascular disease, when compared to those who had controlled and treated their condition (Zhou et al., 2018, Kronish et al., 2016, Barengo et al., 2009). However, the problem of patients not taking their anti-hypertensive drugs regularly has become a global issue (Vrijens et al., 2017). The increased prevalence of hypertension in low and low-middle income countries is associated with low awareness, treatment and control rates of patients (Adeloye, 2014, Agbor et al., 2018).

Anti-hypertensive drugs need to be consumed regularly to control a person's blood pressure to achieve readings confirming an optimal pressure range of <140/90 mmHg (Mancia et al., 2013, Weber et al., 2014). Although drug dosages may be reduced or discontinued without causing a patient to relapse or suffer any harm, very few factors are known which can be used to predict the success of medication withdrawal (Aylett et al., 1999, Scott et al., 2015, Qvarnström et al., 2013). Therefore anti-hypertensive drugs are more likely to be consumed for long periods of time to prevent the adverse effects that hypertension may, and indeed can, cause. On the other hand, long term medication gives rise to a concern over any potential side effects such a long-term regime may cause (Risso-Gill et al., 2015, Marshall et al., 2012). Also needing to be taken into account are the issues of patients' forgetfulness and patients thinking they no longer need the medication, due to them perceiving that they have no more symptoms (Ross et al., 2004, Khatib et al., 2014). Similarly to the implementation of lifestyle modification, the barriers to hypertension treatment are also mediated by other factors, especially in low and low-middle income countries. Such barriers include: 1) the cost of the medication and healthcare services being unaffordable, 2) poor quality service from the health

staff, 3) difficulty in accessing the healthcare centre, and 4) medication availability being intermittent (Yi-Bing et al., 2013, Rahmawati, 2018, Nayeri et al., 2015).

The WHO (2013) has suggested that to harness available testing technology and treatments will require efforts from governments, health workers, research communities, civil society, private sectors, families and individuals. Hypertension control can only be effective in reducing the prevalence of high blood pressure if all the aforementioned stakeholders work collaboratively to encourage both pharmacological and non-pharmacological strategies and ensure their efficacy. However, it was also pointed out that, in the end, all decisions of controlling their blood pressure are in each person's remit; therefore, self management is encouraged as a means to achieving blood pressure control (WHO, 2013, Clark et al., 2014, Deidda et al., 2018, Fau et al., 2013, Bodenheimer et al., 2002). Bodenheimer et al. (2002) claimed self management is a condition when patients have to be their own principal caregivers in controlling their chronic condition; health care professionals act as their consultants. However, even though patients have to be their own caregivers, an easily accessed supportive social network is also essential (Reeves et al., 2014, Vassilev et al., 2013).

Studies highlighted that social interaction can be an adequate source of support for self management, but it can also create negative conditions or circumstances that may cause self management efforts to fail (Vest et al., 2013, Laranjo et al., 2014, Martínez-García et al., 2013, Koetsenruijter et al., 2016). Therefore, the provision of support made available to hypertensive patients is paramount, as its presence could facilitate, or its absence delay, the development of their constructive self management behaviour.

There are various sources of social support available from an individual's total social network, but family and friends can be, and often are, the most influential support resources (Hu et al., 2014, Williams, 2014, Deek et al., 2016, Leslie et al.,

2016, Koetsenruijter et al., 2016, Marquez et al., 2016, Yao et al., 2015). Even though friends may provide support similar to that from families, the patient's family is always top of any social support hierarchy, because family relationships are more stable across the life span (Heinze et al., 2015, Medway et al., 2015, Pedersen et al., 2015, Baig et al., 2015, Li et al., 2014a, Wrzus et al., 2013, Friedman, 1993). Family members can be the closest 'significant others'; the family unit is a natural social support source that provides more enduring care than formal support options (Anderson et al., 2013, Lee et al., 2014, Hudson et al., 2014).

The family, as a provider of social support, has been studied extensively and is known to exert a significant impact on the outcomes of hypertension control (Lee and Park, 2017, Magrin et al., 2015, Hu et al., 2014, Kardas et al., 2013, Li et al., 2013, Bokhour et al., 2012, Ashida et al., 2012, Flynn et al., 2013). Becker and Green (1975), in their seminal work, suggested that the family is able to direct patients in practising compliance behaviour; a process associated with positive family dimensions, especially cohesion and family guidance (Miller and DiMatteo, 2013). It is reasonable to conclude that the more cohesive the family, the better is the control of a member's chronic disease. Therefore, family can have a huge impact on chronic disease management, including hypertension control. To further an understanding of chronic conditions, especially hypertension control within the family setting, the following section discusses the family's role of the patient's closest social support system being the key to hypertension control.

2.4.3 Family as social support is the key to hypertension control

Adopting and maintaining healthier behaviour, such as diet interventions, quitting smoking, reducing alcohol consumption, reducing weight and doing regular exercise, are the central concepts facilitating hypertension self management (Chiu et al., 2016, Santana et al., 2018, Johnson et al., 2015, Yan et al., 2014, Cohen and

Cohen, 2015, Roerecke et al., 2017). Researchers have claimed that if the patients take control of managing their chronic conditions, such a step will produce positive results; specifically: 1) better treatment outcomes, 2) fewer hospital admissions and 3) higher self-efficacy levels (Brady et al., 2013, Free et al., 2013, Chiauuzzi et al., 2015, Ahn et al., 2013, Lorig et al., 2012).

Several established theories in health behaviour, such as a) the health belief model, b) the theory of reasoned action, c) the theory of planned behaviour and d) the trans theoretical model can be used to assist health care providers during the planning of behaviour change programmes at the individual level (Becker, 1974, Prochaska and DiClemente, 1994, Fishbein and Ajzen, 1975, Ajzen, 1991). It is hoped these theories/models can predict patients' intentions regarding changing their behaviour. However, the models have not exploited the significant patient-centric social, economic and environmental factors as predictors and determinants of health behaviour; focus has merely been on the relationship of an individual's perceptions and cognitions with their environment (Taylor et al., 2006b, Jones et al., 2014, Sniehotta et al., 2014, Forward, 2014). As researchers have suggested, behavioural change is unable to happen in a context where it is only influenced by the individual; such change is also informed by that individual's social network (Berkman et al., 2000, Bodenheimer et al., 2002, Hogan et al., 2002, Gorman and Sivaganesan, 2007).

None of the models cited above has explained how to facilitate the maintenance of healthier behaviour as the focal point in hypertension control; all four only predict an individual's intent to change his/her behaviour (Taylor et al., 2006b, Jones et al., 2014, Sniehotta et al., 2014, Forward, 2014). It is arguable that behavioural change could result in effective outcomes if only the new behaviours are maintained (Ryan, 2009, Kwasnicka et al., 2016, Gardner, 2015). In the context of disease management, an individual's social network has been recognised as an

important determining influence on the maintenance of hypertension control-related healthier behaviour (Williams, 2014, Rovniak et al., 2002, Christakis and Fowler, 2008, Christakis and Fowler, 2007, Osler and Prescott, 1998). Close social network members, such as a spouse, can exert a big influence on helping an individual to quit smoking (Jackson et al., 2015, Matthews et al., 2017, Henry et al., 2017). However, the occurrence of obesity has been correlated with an obese spouse, siblings and friends (Skafida, 2013, Gerards and Kremers, 2015, Formisano et al., 2013, de Oliveira Meller et al., 2015, Christakis and Fowler, 2013). As the closest social network for individuals, the family can be the primary health care resource and source of support for its members during both health and illness (Kaakinen, 2010). However, it should be stressed that family members can exert negative, as well as positive, influences on individuals' health behaviour (Powell et al., 2015, Merkel, 2013, Hall, 1985).

An important point in relation to family support to an individual is that even though the family members are available for the individual, sometimes the needed or necessary support may not be given. The interconnected nature of the various dynamic processes makes the family a complex setting, and for its complexity a family can be viewed as 'a system' (Broderick, 1993, Minuchin, 1988, Barnhill, 1979, Bavelas and Segal, 1982, Beckman-Brindley and Tavormina, 1978, Caldwell and Claxton, 2010, Christie-Seely, 1985, Cox and Paley, 2003, Langman, 1984, Zimmerman, 1974). 'Family as system' originated from general system theory developed by von Bertalanffy; the system itself is a complex of interacting elements (von Bertalanffy et al., 2015). System is not 'the whole is greater than the sum of its parts', but there are interrelation aspects within it that have to be considered (von Bertalanffy et al., 2015). A system is self-regulating, which for that feature the parts in a system able to communicate and responds or giving feedback to its parts, when the system experiences deviation due to internal and external sources (von

Bertalanffy et al., 2015). Feedback itself is *“the property of being able to adjust future conduct by past performance”* (Wiener, 2013, p.33). In the ‘family as system’ model, this process is captured when a family keeps adapting to its ecological context through various social relationships, rituals and family life (Bateson, 2000, Bateson, 2005). Therefore, to understand individuals as a part of a family, a ‘family as system’ needs to be studied because the family members’ behaviour is greatly influenced by the interdependency of its members during their daily interactions (Minuchin, 1985, Hammer, 1998). Further explanations of system theory are offered in chapter III (Methodology), section 3.9.3.1 (page 139).

In the next section of this literature review chapter, aspects of challenges that may prevent the family from supporting hypertension control, in the context of ‘family as a system’, will be discussed.

2.4.3.1 Challenges for the family in providing support to improve the patient’s self management

Family involvement in healthy lifestyle modification not only increases motivation to adopt healthier behaviour, but is also believed to help maintain the positive health behaviour changes once they are made (Kelder et al., 2015, Shor et al., 2013). Similar to taking medication regularly, family support is associated with better adherence to anti-hypertensive drugs (Fort et al., 2013, Magrin et al., 2015). Flynn et al. (2013) noted that families are more facilitators than barriers to patients’ self management of hypertension. The family can be the closest social support source that the patients are able to access; support which facilitates self management in changing behaviour and improving treatment outcomes. However, giving encouragement seemingly still can be a challenge for some family members. Ashida et al. (2012) noted that although patients were quite willing to try to change their behaviour, they often failed to do so due to a lack of family support. The lack of

support can be caused by: 1) family members perceiving illness differently, 2) the internal and external factors of the family, and 3) the family's responses toward diseases. Each of the three factors is discussed below.

2.4.3.1.1 Family members perceiving illness differently

Family members' behaviour is greatly influenced by the interdependency of its members during their daily interactions (Minuchin, 1985, Hammer, 1998), so it is reasonable to suggest that individuals' health behaviours are learned in the family (Friedman, 2003). Friedman et al. (2003, p. 49) suggest health care is one of the basic functions of the family, and with this function the family aims to meet its members' health needs. In terms of disease in a family setting, its perception is predominantly influenced by the severity of illness and certain background variables such as gender and age of the family members and of the patient (Åstedt-Kurki et al., 2004). Power and Dell Orto (2004) suggest recovery from illness and effectively coping with health issues may be hindered if those involved, such as medical personnel, patients and family, have different perceptions of illness. Family support in treatment management may be lacking as the result of family members perceiving the meaning of illness differently from the patient. For example, in a family from an Asian cultural background, collective intergenerational care is unavoidable (Johar and Maruyama, 2011, Kim et al., 2015, Khan, 2014, Ko and Hank, 2014, Lin and Yi, 2013, Teerawichitchainan et al., 2015, Chang, 2013, Knodel and Pothisiri, 2015, Kreager and Schröder-Butterfill, 2008).

Traditionally the main care-providing duty in a family rests with spouses, mother and/or daughter (Power and Dell Orto, 2004, Aschbrenner et al., 2012, Flynn et al., 2013). Hypertension may be experienced by the parents or grandparents, which causes their spouses, children or grandchildren to get involved in the task of disease management. Blaxter and Paterson (1982) in their seminal work suggested

several concepts which may be similar or different between different generations: 1) health, illness and disease, 2) perceptions of symptoms, 3) attitudes to medicine, 4) attitudes about health professionals, 5) perceptions of lay remedies, and 6) referral. The researchers suggested that older generations sometimes 'normalise' their chronic condition by ignoring or pretending that they do not have any illness; a denial defence mechanism that causes potentially harmful delays in seeking access to health services. In contrast, younger generations have more concerns about symptoms and therefore they use the health services that are available.

This generational difference may create barriers to hypertension control within the family. As Flynn et al. (2013) have shown, younger family members reported that their parents have lower motivation towards hypertension self management, which can then lead to uncontrolled hypertension if not dealt with. The condition portrayed by Flynn et al. (2013) is associated with the condition of hypertension that has been recognised for its symptomless characteristics, although it is actually a condition that could lead to fatal consequences such as cardiovascular disease, stroke and/or kidney problems if left uncontrolled (Bakris et al., 2018b, Acelajado et al., 2013, Bloch and Basile, 2007, Burnier and Wuerzner, 2015). Uncontrolled hypertension is associated with lower support levels from those families who have poor knowledge about hypertension (Flynn et al. 2013). Such families lack the awareness that hypertension could increase the risks of mortality and disability if it is not treated. Regarding a lack of information among family members, a study by Lo et al. (2016) showed that hypertensive patients who lived in senior group housing were more likely to have controlled blood pressure, compared to those who lived with their family. The researchers suggested the reason for that outcome was because the elderly living in senior group housing were more often involved in social interactions and conversations about health than individuals in families. In addition those

patients in group housing received more encouragement to take their anti-hypertension drugs than the family dwellers did.

Hypertension is also known as a condition that rarely shows any easily noted symptoms until organ damage occurs (D'Agostino et al., 2008, Kokubo et al., 2015, Levy and Faraoni, 2016, Acelajado et al., 2013, Burnier and Wuerzner, 2015, James et al., 2014, Franco et al., 2007, Izzo, 2017). Therefore hypertension is often referred to as a 'silent killer', due to its mainly asymptomatic nature. However, for some sufferers hypertension can cause annoyingly inconvenient symptoms such as headache or a stiff neck (Ferguson et al., 2010, Feldstein, 2014, James et al., 2014). Hypertension is a common condition which predicts the possibility of a patient developing cardiovascular disease (CVD) in the future. Despite serious complications resulting from uncontrolled hypertension, such as strokes and CVD, hypertension is not considered as a disease *per se*, but only as a risk factor associated with heart disease (Espejo et al., 2018). Moreover sometimes hypertension is considered to be of relatively little importance because it makes only a minor impact on patients, compared to other chronic conditions such as diabetes (Anthony et al., 2012). The perception of hypertension being a less important disease has only served to increase the rate of patients non-adherence to managing their condition (Hsiao et al., 2012, Anthony et al., 2012). Furthermore, hypertension is considered to be a stable and controllable condition, whose patients express confidence only in the effectiveness of medication for their treatment (Sångren et al., 2009, Hsiao et al., 2012).

On the other hand, studies reveal the family significantly influences the efficacy of patients' hypertension control (Cuffee et al., 2014, Cornwell and Waite, 2012, Shen et al., 2017). According to the patients, their families provide support for them, such as company to prevent patients from feeling lonely; the outcome of which is lower systolic blood pressure (Cuffee et al., 2014). In addition, patients'

adherence to medication also improved when the family supervised the patient actually taking his / her medication (Campbell et al., 2015). Support from a spouse has also been shown to significantly improve hypertension management in general (Cornwell and Waite, 2012). Family members potentially affect individuals' and families' health, as they encounter similar and dichotomous experiences throughout their lives. All these experiences, whether relevant to hypertension or not, will be shared within the family through the interactions, relationships and transactions of its members (Denham, 2003). In addition, family members are sometimes more knowledgeable than health professionals in terms of their own caring arrangements, thereby helping to improve disease management efforts (Nolan et al., 1996, Miller and DiMatteo, 2013, Rintala et al., 2013).

While the patients perceive that their families support them in controlling hypertension, according to family members, the patient is the person above all others who is responsible for dealing with, and managing, their condition. The responsibility, it is strongly suggested, does not rest totally with the family. This attitude derives from the fact that hypertension is not generally considered by the family members as being a severe condition (Antonio Del et al., 2013). Similar to the study by Antonio Del et al. (2013) about the perceived severity of the disease, Rao et al. (2014) revealed that the compliance toward diabetes treatment was higher than hypertension treatment, because the asymptomatic nature of hypertension ensured it was perceived to be less severe than diabetes. From the study by Antonio Del et al. (2013) a contrary perspective was seen to exist between the patients and their families. The study shows significantly different perceptions relating to hypertension control between patients and their families. Any unclear communication or misunderstanding of transactions, during the receiving and giving of support between the patients and their families, potentially compromises the quality of hypertension control. It is important to address the individual's lay

perspective of illness, as it is the family's perspective about hypertension that will dictate behaviour when it comes to providing support for the patient's self management.

In addition to family members perceiving hypertension differently, the other challenge of hypertension control within a family setting is the internal and external issues faced by the family; an issue that is discussed in the following section.

2.4.3.1.2 Internal and external factors of the family

von Bertalanffy et al. (2015) considered a living organism as an open system because of its continuous and irreversible process of maintaining its composition by exchanging matter with its environment. A family is a living organism and is considered to be an open system, because a family is unable to live in isolation. The family, with its constituent members, will always need to exchange matter with their environment and *vice versa* to maintain a steady state (von Bertalanffy et al., 2015, Stanton, 2010, Datchi-Phillips, 2011, Bavelas and Segal, 1982). Similarly, for the self management that is required in hypertension control, the process will be influenced by internal and external factors associated with the family. Individual and family engagements in self management are challenged or protected by condition specific, physical and social environmental, individual and family factors (Ryan, 2009).

Ryan (2009) adds the 'condition specific' refers to the characteristic of the disease, its treatment and prevention. Meanwhile the individual and family factors include: 1) family members' cognitive status, 2) family capabilities, 3) family cohesion and 4) resourcefulness. In this section the condition specific and individual and family factors are included as internal factors influencing hypertension control. The environmental factors both physical and social are then treated as external factors. These two categories are discussed in the following section.

2.4.3.1.2.1 Internal factors

Treatment of hypertension requires a patient's adherence to medication and adopting a healthier lifestyle. The latter involves: 1) diet plans, 2) exercise, 3) stress management, 4) quitting smoking and 5) reducing alcohol consumption. The implementation of behavioural change has to be done regularly and consistently and is affected by household practices (Denham, 2003). Those practices are the results of the family's functional processes or are the "ways members interact to potentiate, negate, threaten, mediate and enhance individual and family health" (Denham, 2003,p.123). A study by Gallant (2003) has shown a part of the functional process: patients purposely limit their contact with unsupportive others and family members who are unwilling to adjust their own diets, even though patients need to follow strict diet plans. In addition, recent research by Flynn et al. (2013) suggested if a similar condition is experienced between another family member and the patient, then this could facilitate the patient's self management. However, it has also been observed that poor health conditions and limited knowledge about hypertension can be barriers to helping patients with their self management. Those studies have shown various factors affecting, either positively or negatively, the family's support in facilitating a member's hypertension management. Olson (2000) suggested that family cohesion, flexibility and communication impact a person's ability to change their health habits. Functional processes, such as caregiving, change, communication and coordination may be relevant to hypertension management. Such processes' potential functional areas are concerned with: 1) health maintenance, 2) disease prevention, 3) risk reduction, 4) health promotion, 5) chronic concerns, 6) control, 7) knowledge, 8) skills, and 9) decision making.

Another internal factor that can also be a predictor in self management engagement is family cohesion (Ryan, 2009). Family cohesion is defined as *emotional bonding that family members have toward one another* (Olson et al.,

1983, p.1). Family cohesion is expected to promote family support; a low level of family cohesion is associated with an increased risk of psychological distress (Rivera et al., 2008, Vidal de Haymes et al., 2011, Hosseinkhanzadeh et al., 2013, Mitchell et al., 2016, Anyan and Hjemdal, 2018). Meanwhile, stress has often been associated with blood pressure elevation (Cottingham et al., 1986, Larkin, 2005, Rainforth et al., 2007, Bokhour et al., 2012, Dusek et al., 2008). Stress is also believed by many patients to be the cause of their blood pressure elevation (Akinlua et al., 2016, Angela Maria Geraldo et al., 2016, Duwe et al., 2018, Fava et al., 2013, Flynn et al., 2013). Bokhour et al. (2012) suggested family is one of the most significant sources of stressors. In addition, their study also revealed that situational stress affected hypertension control in a negative way. Bokhour et.al (2012) found that situational stress from within the family weakens the patients' medication adherence. This outcome is because the patients prefer to control their stress, if it is perceived as the problem's cause, rather than take their medication.

On the other hand, patients with more emotional support from their families, and who live surrounded by less stressful social networks, have been associated with a lower risk of experiencing uncontrolled hypertension (Cornwell and Waite, 2012). These researchers added that the size of the family was not necessarily related to the risk of uncontrolled hypertension, as was generally assumed, but the size of family is related to the likelihood of communicating with family members about health issues. Both studies (Bokhour et al., 2012, Cornwell and Waite, 2012) captured the interconnectedness, and interdependence of the patients with their families, as seen from the patients' perspectives. However, which processes that were involved in stress resulting from the family relationships that mediate hypertension control, remains unclear. Furthermore, stress experienced by the family arises because the family perceives an imbalance between 'demand-capability' that is characterised by multidimensional demands for adjustment

(McCubbin and Patterson, 1983). The only a part of the system that was thoroughly researched was 'patients'. A patient as an individual is a part of a family that is unlikely to be isolated from the other family members' influences. As Broderick (1993 p.37) suggests: a family is "a complex interacting system, an ongoing, goal-seeking, self-regulating, social system" and transformation in a family, especially correlated with behaviour change, can be explored through its interconnected elements.

In addition to internal factors, external factors can also be significant determinants in hypertension control and are therefore discussed in this next section.

2.4.3.1.2.2 External factors

The external factors in this review focus on physical and social aspects of the patient's external environment that may influence hypertension control. Ryan (2009) mentions that physical and social factors influence engagement in self management for both individual and family. These same factors play their parts in BP control, because hypertension is related to many socioeconomic factors that directly, or indirectly, affect its management (Brummett et al., 2011, Bokhour et al., 2012, Egan et al., 2014, Alsabbagh et al., 2014). According to Bronfenbrenner (1992), considering individuals' and groups' environments is essential if one wishes to understand their behaviour. Bronfenbrenner (1992) suggests the ecological components of the concept 'family' include: 1) a microsystem, comprising of relationships and interactions, 2) a mesosystem, comprising a microsystem and processes involved, and 3) an ecosystem, involving external social environmental factors.

The physical environment significantly mediates the adoption of healthier behaviour (Chor et al., 2015, Bokhour et al., 2012, Ewing et al., 2014, Zick et al.,

2013, Tehrani et al., 2016, Wood et al., 2013, Brown et al., 2014). For example the physical environment is strongly associated with physical activity levels, the reduction of a person's body mass index (BMI), and also lowering obesity (Chor et al., 2015, Ewing et al., 2014, Tehrani et al., 2016, Wood et al., 2013). Ewing et al. (2014) revealed that residents in compact counties in the US have lower BMIs, thereby reducing the risk factor of obesity, compared to those living in sprawling counties. According to Ewing et al. (2014) residents in sprawling counties are more dependent on automobiles, while those who lived in compact counties have lower dependencies to automobiles, and high in walking mode shares on work trips.

Other than physical activity, the environment is also associated with diet changes, such as non-profit community garden interventions that succeed in increasing fruit and vegetable intake among participants in gardening activities (Zick et al., 2013). Zick et al. (2013) showed easy access to fruit and vegetables creates healthier diets, as well as improving less healthy eating, among society. Another important impact of the physical environment on diets is its influence on food intake and BMI. Studies reveal that the environmental conditions of residents who live close to fast food outlets and convenience food restaurants are associated with higher BMIs, when compared to those living further away from such outlets (Davis and Carpenter, 2009, Currie et al., 2010, Li et al., 2011).

Primarily such studies investigated the physical environment, seeing it as a very important risk factor in the development of chronic conditions, mainly focusing on healthy populations (Davis and Carpenter, 2009, Couch et al., 2014, Ewing et al., 2014, Currie et al., 2010, Li et al., 2011). However, a study by Bokhour et al. (2013) investigated daily hypertension management from the patients' point of view. One of the findings noted how the physical environment influenced the physical activity levels among the patients. This study revealed the physical environment, such as unsafe neighbourhoods, inhibited the patients from participating in exercise, even

though they were aware of the importance of regular exercise as a way of controlling their blood pressure. Other studies were conducted using qualitative approaches to investigate the patients' experiences of hypertension control (Shamsi et al., 2017, Jolles et al., 2013, Hallberg et al., 2016).

The results of those studies included the physical environment's impact on physical exercise, but unfortunately overlooked the physical environment's impact on diets. In an Indonesian context the physical environment's impact on practices of hypertension control has been ignored. Studies in Indonesia predominantly looked at the patients' adherence to medication and the barriers preventing the regular taking of medication (Rahmawati, 2018, Helble and Aizawa, 2016). Cross-sectional studies investigated correlations between socio-economic status and incidents of hypertension (Peltzer and Pengpid, 2018, Julia et al., 2006, Ng et al., 2006, Tuan et al., 2009a). The non-pharmacological approach should have been studied as thoroughly as the medication approach, in order to improve the efficacy of hypertension programmes. However, there is very little evidence of non-pharmacological interventions, especially regarding diets and physical activities. The barriers and facilitators that the physical environment may create for these aspects have yet to be investigated.

In addition to the physical environment, the social environment is also associated with hypertension control. The concept of 'social environment' has been defined as:

"The immediate physical surroundings, social relationships, and cultural milieus within which defined groups of people function and interact social relationships, and cultural milieus within which defined groups of people function and interact" (Barnett and Casper, 2001, p.465).

In this literature review the social environment refers to social relationships, especially the wider social networks outside the family, together with cultural milieus; both of which are elaborated below. Families cannot live in isolation, instead they live in an elaborate system of interactions that enables them to create

ties, at various levels of complexity and strength, with a broad array of individuals, other families and larger social collectives (Milardo, 1988). Milardo (1988) also suggested that families are not only greatly influenced by the ties they create, but also are active agents in modifying and adapting these communities of personal relationships to meet ever changing circumstances. In terms of health behaviour adoption, studies have revealed the wider social networks outside the family such as those featuring: a) the work place, b) school, c) neighbours and d) friends have influenced the adoption of healthier behaviour (Laranjo et al., 2014, Berkman et al., 2000, Christakis and Fowler, 2008, Cornwell and Waite, 2012, Moore et al., 2009, Mulvaney-Day et al., 2012, Powell et al., 2015, Shaya, 2010, Wrzus et al., 2013, Legh-Jones and Moore, 2012).

For example, social networks involving friends have greatly influenced individuals' decisions over health practices, such as the use of complementary alternative therapies (CAM) (Murthy et al., 2017, van der Schee and Groenewegen, 2010). Meanwhile, when American adult patients are introduced to CAM, they are more likely to use an alternative treatment option than Western medicines (Goldman and Cornwell, 2015). This condition potentially influence patients' adherence to medications, affecting their treatment programme and eventually the treatment's outcome (Murthy et al., 2017).

Additionally, family as part of a social collective is a culture-bound phenomenon (Parsons, 2014). For a family, culture provides norms for behaviour that consequently affect the family members' roles and power dynamics (Johnson, 2013). Moreover, Hays (1994, p.65) suggests:

“Culture is both product of human interaction and the producer of certain forms of human interaction. Culture is both constraining and enabling.”
Thus culture predominantly provide guidelines for communities, informing them how to live in 'right', 'true' and 'good' ways (Shweder, 2003); consequently culture informs and is embedded in health behaviour (Melnik et al., 2016, Axelson, 1986).

An important aspect of health behaviour that is strongly influenced by culture is diet (Ma, 2015, Levine et al., 2016, Frederick et al., 2016, Axelson, 1986). For example, food preferences are often associated with social status (Ma, 2015, Kinaston et al., 2013, van Overveld et al., 2018). People from higher social classes consume more foods from animal sources that are rich in protein (Ma, 2015, Kinaston, et al., 2013). For the upper classes in society, those foods represent their class and differentiate them from the lower classes. As Palma et al. (2017) suggest, income cannot be directly observed by others, therefore showing the overt, visual consumption of goods is an important way to display wealth and purchasing capacity. Meanwhile, foods rich in protein, especially of animal origin, have been associated with various chronic diseases such as cardiovascular issues, cancer, and diabetes (Schulze et al., 2018, Anand et al., 2015, Chiu et al., 2016, Hallström et al., 2015, Kahan and Cheskin, 2014, O'Neill, 2015). Culture can be a guideline to living in right, true, and good ways for some societies, but may not be so helpful for others.

Another example of cultural differences which shape healthy diet practices is the issue of independent and interdependent cultural norms (Levine et al., 2016). Levine et al. (2016) suggest independent norms that apply in American society promote healthy eating by offering: a) many healthy foods options, b) multiple methods in healthy eating to fit those with busy schedule, and c) other efforts to ensure individuals' independence in healthy eating. This norm not only predicts balanced healthy eating, but also predicts extreme behaviour; such as being over-trained, too healthy or very unhealthy; such as weight loss through starvation.

In the interdependent context of Japanese society, healthy eating means sharing healthy recipes. Cooking and eating practices are orientated to the family unit so that meals are enjoyed by the family, with members eating together and maintaining strong relationships (Levine et al., 2016). This Japanese norm also helps to ensure that healthy food is available to every family member.

Diet is an important aspect in the majority of chronic diseases management cases. Diet has been strongly linked to an individual's cultural background; therefore, in discussing chronic disease management, including hypertension, cultural dimensions have to be included in the investigation. I was unable to identify any research in an Indonesian context that discussed cultural impact on hypertension management. The main focus relates to demographic data and hypertension control, without any deeper analysis focusing on the influences of culture (Tuan et al., 2009b, Hussain et al., 2016, Sohn, 2015, Rahman et al., 2015a). This omission is despite the fact that Indonesia is a multicultural country. Furthermore, cultural aspects have been revealed to significantly affect hypertension control initiatives in other countries (Kressin et al., 2007, Beune et al., 2014, Neela et al., 2012)

Skelton et al. (2012) suggest the environment can potentially either stimulate unhealthy behaviour and / or exert great positive influence on health behaviour transformations. Family interactions with the social environment (ecosystem) are also important and a subject to be considered. In alignment with Skelton et al. (2012), it is essential to understand from the family's point of view, what are the circumstances and environmental pressures which could facilitate or hamper the matter of blood pressure control.

Even though family members are the closest support available for the patients, but their response toward certain disease might be different which then potentially affect their support for the patients. Therefore, the following section further discusses the family responses toward diseases.

2.4.3.1.3 Family responses toward diseases

Power and Orto (2004) have argued that each family member may respond differently to a medical event; an outcome which could be disruptive if family

members began blaming each other or showing very limited tolerance for the patients. However, it is equally possible family members may respond positively to their care-role challenges, such as showing optimism, faith, courage and mutual support for the member-patient. Encouragement by family members has improved patients' motivation to adopt healthier behaviour; for example, eating more fruit and vegetables, as well as taking part in physical activities (Ashida et al., 2012). Family responses to members' medical events may provide information about a family's ability to cope with illness or a disability situation (Power and Orto, 2004). Chronic illness is a condition that requires patients and families to cope with daily obligations and challenges, such as food preparation, which involve many individual episodes and events. There might be serious 'impacts', such as untreated hypertension increasing the risk of hypertension; equally, there are also certain conditions that may be improved or that may worsen (Kleinman, 1988).

Most studies that examine individual experiences in relation to disease management have suggested that social support, especially from their family, is essential in helping patients to manage their chronic condition and/or to implement a healthier lifestyle (Flynn et al., 2013; Bastawrous et al., 2014 Baker et al., 2003; Gallant, 2003; Ashida et al., 2012). From the family's point of view, to be one of several support resources for their significant others, in managing a chronic condition, could give rise to various reactions and perceptions. These responses could be challenging, satisfying, or affecting their relationships with the patients, both in positive and negative ways (Flynn et al., 2013). Diverse responses toward a condition in a family shows a family as comprised of complex active agents (Handel, 1996). Each member has a unique position in, and perspective on, the group (Mead, 2015). However, many studies show the data sources of family involvement in disease management are limited to one family member, such as the spouse or an older child (Baker et al., 2003, Gallant, 2003, Flynn et al., 2013, Bastawrous et al.,

2014). It seems that responsibility for giving care to patients normally rests with just one adult family member; patients seem to affect, and are affected by, the support of that one carer. Handle (1996, p.343) states:

“Every family member has a particular kind of interest in every other member of the family so that each is endeavouring to communicate those several interests, while also receiving communications of interests that are often not compatible or congruent.”

The above statement emphasises that relationships impact the action of each individual with the other family members; potentially resulting in diverse responses toward medical conditions. The traditional extended family is a model which is still prominent around the world especially in Asia, the Middle East, South America and Sub –Saharan Africa. In such families patients affect, and are affected by, other family members, meaning more active agents are involved in the interactions. Such a context has the potential to trigger more diverse responses toward a member's medical condition (Child Trends, 2013).

This literature review focuses on the family's response to hypertension control, because daily hypertension control is mostly embedded in family daily practices, such as food preparation, stress management and taking medication. Hypertension is viewed as a lifestyle disease; there is significant evidence to suggest that healthier diets which are low in sugar, low in salt and low in saturated fats, help to lower high blood pressure levels (Hinderliter et al., 2014, Herrod et al., 2018, Lenz and Monaghan, 2008, Pouliou et al., 2012, Lancaster et al., 2014, Appel et al., 1997). In relation to the family, food preparation is essential to daily family life. Separating diets, meals and families is impossible. Jackson (2009, p.1) said “*food is a lens on family life*”, suggesting a family's dietary practice is a useful way to understand changes in a family, and *vice versa*. A family meal is an important routine and aspect of family life; the event can be perceived as a reflection of the individuals' health in their family. For example, the frequency of family meals is associated with the nutritional status and development of risk factors among

adolescents; the more frequent the family meals the better the adolescents' nutritional status, with fewer risk factors from diet-related health issues (Neumark-Sztainer et al., 2013). Frequent family meals might yield positive impacts on health outcomes, but the foods chosen for those meals are a critically important aspect of nutrition. Families who tend to choose unhealthy foods that are rich in saturated fats, salt and sugar, increase the family members' weight status, often leading to obesity amongst other health issues (Couch et al., 2014, Chan and Sobal, 2011, Berge et al., 2012).

The interconnectedness in a family inevitably influences the food preferences and patterns of eating. As Ferzacca et al. (2013) argues: i) environmental, ii) social and iii) cultural factors and values strongly influence a person's food preferences and choices. In addition to the triadic influence, food preference decisions also represent a 'personal system'. Such a system is seen in the development of an individual's cognitive processes when making food choices that serve to control that person's eating behaviours in certain settings (Sobal and Bisogni, 2009). The combination of those three influences, together with the 'personal system', make food choice decisions: frequent, multifaceted, situational, dynamic and complex (Sobal and Bisogni, 2009, S.42, Ferzacca et al., 2013).

As for food preparation, Morgan (1996,p.158) argued: "*the major axis around which the micro-politics of food revolves is to do with gender*". Morgan (1996) adds, responsibility in kitchen largely fall into women's remit, especially for the food preparation. Similarly food preparation in a family setting in Indonesia is assumed to be the women's responsibility (Schaner and Das, 2016, Nobles and Bутtenheim, 2008, Elfrida, 2017). According to Morgan (1996) women inherit knowledge in cooking techniques from other women informally, such as passed down from mother to daughter, thus they develop more knowledge than most men. As a result of socio-cultural conditioning that makes women better cooks than men, in addition

knowledge represents a form of power and control (Morgan, 1996, p. 160) cause women have more control over the kitchen domain. Such an authority helps women to occupy the central position in the family, thereby enabling them to assert their own needs and interests (Björnberg, 2005). From their central position of kitchen-related authority women decide what is to be cooked, when it is to be cooked and how it will be cooked (Morgan, 1996). In families without any members having a chronic condition, children's choices are often prioritised when preparing meals within the family (Minas et al., 2013, Russell et al., 2015, Slater et al., 2010, Wang et al., 2014).

The patient's food consumption is an important aspect of hypertension control; however, whether the need to provide healthier foods for hypertensive patients will be a priority within their family has not been adequately explored. The studies of diets designed to counter hypertension have discussed the effectiveness of certain diets or diet-related interventions as ways of reducing blood pressure levels (Yokoyama et al., 2014, Webber et al., 2013, Bull et al., 2006). There were attempts to include the family in studies, but the studies were conducted using a quantitative approach, including only one family member in the research population (Reid et al., 2018, Bhattacharya et al., 2018). Similarly, qualitative research was conducted to investigate family inclusion in hypertension control; however, only the hypertensive patients were included as participants, with the family members being omitted (Gehlawat et al., 2018). Meanwhile Handel (1996) suggests that in order to portray a family as a unit, it is important to understand the 'meaning' of each family member to all the other members, acknowledging that those meanings are jointly created. In order to understand the family's response toward hypertension it will be necessary to study the family members who have close relationships with the patient in daily life. This focus will not only be on the primary carer, because individuals in a family,

including the patient, are all engaged in a “*multi-personal web of interaction*” (Handle, 1996, p.343).

2.4.4 Summary

Hypertension management aims to control SBP <140 mmHg, and DBP <90 mmHg for individuals aged <60, and 150/90 mmHg for those aged ≥60. Self management for both pharmacological and non-pharmacological initiatives is encouraged as a way to control hypertension. However, implementation in real life of all, or even some, of the suggested options might be difficult to achieve, because several barriers to hypertension control exist, especially at the individual level. The individual barriers include internal barriers, as well as those coming from the individuals themselves, or from their socio-economic and/or cultural backgrounds that could present significant obstacles to the health management initiatives.

The self management approach encourages patients to be their own caregivers, but it should be emphasised that an easily accessed, supportive, social network is also essential for the individuals who are the patients. As for social support for individuals, families are always at the top of any social support hierarchy, because family relationship are likely to be more stable across the life span than other types or categories of support. However, even though families can provide influential support for individuals, families can also create negative circumstances that may cause self management efforts to fail or for necessary support to become unavailable. Lack of support may potentially be caused by several factors including: 1) family members perceiving illness differently, 2) the internal and external factors of the family, and 3) the family's responses toward diseases. Family, as a complex setting, contains interacting and interconnected elements, with its members being active agents who construct family life. Therefore to understand the implementation of hypertension control initiatives at the individual level, the family as a system

needs to be studied, because family members' behaviour is greatly influenced by the interdependency of its members during their daily interactions.

The following chapter discusses the methodology used in this study, based on the research gaps identified in the previous sections.

3 Methodology

3.1 Introduction

This chapter presents the methodology chosen to address the research gaps identified in the last chapter. The research aim and research questions are also presented. Following the research aim and questions I present the justification for the methods chosen to answer the research questions; a presentation that includes the theoretical underpinnings of the research design and the rationale for choosing focused ethnography. In the following sections the key issues of: 1) research methods, 2) study settings, 3) study participants, 4) data collection, 5) data analysis, 6) reflexivity, 7) ethical considerations, 8) methodological rigour and 9) translation considerations, 10) research limitations are discussed.

3.2 Aim of the study and research questions

Based on the knowledge gaps identified in the literature review, this study is designed to set out the families' experiences in daily hypertension control in Denpasar, Indonesia. In order to gain an understanding of families' experiences in hypertension control, in relation to stress, diets, roles, responsibilities, and the characteristics of hypertension, three main research questions were formulated:

1. In what ways do family members experience the impact of an individual living with hypertension within a family group?
2. How do family members experience the management of an individual's hypertension control within the family group?
3. What are the potential facilitators for, and barriers to hypertension management in families?

The research questions guide the research design and the following section offers justification for that design.

3.3 Focused ethnography as a contemporary research method

In the late nineteenth-century ethnography was a research method designed and used specifically for anthropological studies. The approach involved extended participant observations, requiring the researchers to travel far away to reach unfamiliar research settings, often to observe communities that were outside the West (Hammersley, 2010). The political changes related to Western imperialism shifted the location of ethnographic studies from remote communities to settings 'at home' (Savage, 2000). In the twentieth century ethnography became an important model for some strands of research within Western sociology, mainly focused on the study of urbanisation in the US and Western Europe (Hammersley, 2010). The development of ethnography in the twentieth century was hugely influenced by sociologists affiliated with the University of Chicago and this ethnographic form further spread across many sociological sub-fields, as well as other disciplines and areas (Hammersley, 2010, Atkinson et al., 2007).

Ethnography has been widely used as an alternative method to the quantitative approach for studying healthcare delivery systems (Finn et al., 2010, Leigh and Matt, 2011, Greig et al., 2012). Leigh and Matt (2011) suggested that healthcare settings are complex and therefore need a method that is able to provide very thick descriptions of underlying issues. They also highlighted the point that ethnography in healthcare settings avoids trial-and-error solutions, because ethnographic study will direct the investigator to the root issues of patient care, which would then lead to the 'real' solutions.

One of the adaptations of ethnography to be found in health care settings, and which is widely used in the field of nursing care, is 'focused ethnography' (Roper, 2000). Focused ethnography is a branch of ethnography in social research that is also popular in the forms of mini- ethnography and micro-ethnography (Knoblauch, 2005, Roper, 2000). A characteristic of traditional ethnographic research is its

'funnel' structure, being progressively more focused over its course. Meanwhile focused ethnography's main characteristic is that the researcher has prepared specific, issue-focused questions before beginning the information gathering fieldwork (Hammersley, 2010, Roper, 2000; Knoblauch, 2005). In addition, classic ethnographic studies are conducted amongst a foreign group of people or culture outside the West and characterised by the researcher's long term interaction with the group being studied (Muecke, 1994, Mayan, 2016). Thus, in classic ethnography researchers as outsiders enter an unfamiliar cultural setting with a broad, undefined purpose (Richards, 2012). Meanwhile, in conducting focused ethnography, the researcher takes the role as insider or has background knowledge of the cultural group, due to short-term or absent field visits (video recording to replace field observations) (Higginbottom, 2013, Knoblauch, 2005, Morse and Richards, 2002).

Focused ethnography is applied within a specific context among *a small research population* to seek to understand a particular problem (Roper, 2000). Focused ethnography shares the core values of classical ethnography, including: 1) conducting participant observation in natural settings, with minimal influence on those being studied, 2) trying to understand the actions and events at the field sites and 3) applying multiple data collection methods (Roper 2000). On the other hand, some features differentiate both approaches, such as: 1) shorter on-site visits, 2) pre-selected research questions focused on certain issues, and 3) due to time constraints, investigators will already have some background knowledge related to the specific topics under scrutiny (Knoblauch, 2005). Focused ethnography uses various strategies to produce significant amounts of data in short periods of study. Knoblauch (2005) suggested that in focused ethnography the researcher is able to use different recording devices such as: 1) video camera, 2) voice recorder and 3) photo camera, in addition to conventional strategies such as interviews and participant observation.

In nursing, focused ethnography has gained popularity because of its promising potential to enhance nursing practice (Cruz and Higginbottom, 2013). Study results using focused ethnography allow transferability, because the method bridges the gap between traditional ethnography, which develops knowledge, and adapted forms of ethnography that are conducted to address practical problems (Wall, 2015).

A focused ethnographic study by Higgins and Learn (1999), has shed light on health practices of adult Hispanic women in New Mexico's urban areas. The study's main conclusion was those women will place family's health first and their own last. This result suggests those professionals in nursing practice should not make any positive assumptions about Hispanic women's knowledge of health. They received health information, but were unlikely to practice or be informed by it. Therefore, nurses and other healthcare staff needed to improve their practices to enhance those Hispanic women's health. Another study by Gerrish et al. (2013) also sheds light on healthcare practices. She employed focused ethnography to scrutinise the experiences of Somalis with tuberculosis and their interactions with healthcare services in the UK, during both the diagnosis establishment and TB management. The study has shown a lack of awareness regarding TB relative to stigma among the Somalis about the disease, which then leads to low clinical suspicion levels among general practitioners that could delay the diagnosis of Somali patients with tuberculosis.

Focused ethnography is a study method involving a researcher's submersion into the settings, equipped with pre-defined questions to generate data within certain contexts and cultural landscapes that have been overlooked by quantitative research (Bikker et al., 2017, Goodson and Vassar, 2011)

3.4 Focused ethnography for family studies

This current study has employed a focused ethnographic research approach directed towards families' experiences in daily hypertension management. The research directs specific attention to obtaining information regarding how Indonesian families manage when one of their members is suffering from hypertension. This section discusses the background issues relevant to using precisely focused ethnography as a research method in family research.

Geertz (1973) emphasised that humans and culture cannot be separated; to understand the former we need to involve the latter. Culture itself has been defined as 'a particular set of observable behaviours, customs, way of life, ideas, beliefs and knowledge that characterises a certain group of people' (Fetterman, 1989). Culture is a delicate matter; all human behaviour, interaction and practices in daily life are influenced by culture. Therefore to understand a specific culture, an interpretative research model in search of meaning is preferred, rather than an experimental one (Geertz, 1973). Ethnography has a long history as a chosen method to capture the sense of humans and their cultures in everyday life (Hammersley, 2010).

This current study aims to understand families' experiences in the practice of daily hypertension management of one of their members; thus, the focus of this study is 'families with their members identified with hypertension.' The family plays a major role in disease management, particularly as a change in one member very often affects all the other family members (Wright, 1994). The system framework sees 'family' as interconnected. Thus the dynamics and complexity of a family can be understood by viewing the elements of the family as interconnected and interrelated or seeing the family as a system (White, 2015). Furthermore Handel (1996, p.344) conceptualises:

"Families as a complex active agents in constructing their own family life, and we conceptualize each family member, each child as well as adult, as an

agent whose actions contribute to shaping that family's interdependent life together-and apart."

Handel (1996) adds obtaining information from one family member is not sufficient to obtain the whole picture of the family. Multiple perspectives of its member have constructed family life, and an adequate understanding requires that those perspectives be obtained from their multiple sources. Recognising the interconnected nature of a family means that gaining any understanding or knowledge about such a system will require interactions with that family system. Therefore, constructionism is adopted as the epistemological assumption for my study, as it suggests that truth or meaning cannot be *discovered* but is *constructed* through engagement between human beings and the world (Crotty, 1998).

3.5 Epistemology considerations

This section addresses the epistemological considerations that inform my study. In this research I wanted to explore the families' experiences in daily hypertension control in Denpasar, Indonesia. As such, I considered the family as a system, with each part interconnected and influencing each other, both as participants and sources of information.

The constructionism view is:

"All knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context." (Crotty, 1998, p.42)

The constructionist's perspective emphasises that reality is the result of the everyday activities of human beings, and therefore constructionist focuses on humans' interactions with other human beings (Silverman, 2013). Therefore, by adopting a constructionist epistemology, I perceive the knowledge and meaning of families' experiences in hypertension control to be constructed by: i) the interactions

between family members, ii) interactions between the family members and their environment, and iii) by ordinary activities within the family. The construction of hypertension control within the family shows the feedback loop characteristic of family as a system, that if 'a part' expresses an action, then there will be reaction from the 'other parts'.

Within constructionist, knowledge is generated and transformed in social life through communication and everyday interactions (Holstein and Gubrium, 2008). Therefore for me, as the researcher, to engage in daily family life was essential if I were to understand the issue of hypertension control within the family context. This approach allows a researcher to describe observed realities and how the social actors construct and sustain those realities in everyday life (Holstein and Gubrium, 2008). This approach enables me not only to describe what the families have done in controlling hypertension but also to understand their reason or reasons for those actions. In order to be able to gain understanding of participants' everyday lives, it is important to gather data by conducting observations that are informed by symbolic interactionism (Hammersley, 2010); a concept which is elaborated in the next section.

3.5.1 Symbolic interactionism as the theoretical perspective

Symbolic interactionism is chosen as the theoretical perspective informing the method of this current study with the assumptions in line with those of (Blumer, 1986):

- That human beings act toward things on the basis of the meanings that these things have for them.
- That the meaning of such things is derived from, and arises out of, the social interaction that one has with one's fellows
- That these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters

Based on the perspective of symbolic interactionism, a researcher experiences the social phenomenon under scrutiny as the actors experience them (Coser, 1971). This perspective explains that the social world is a place of process, rather than static. People and objects are evolving and could well possess intertwined local identities that may not be revealed at the outset, or to an outsider (Rock, 2001). The processes found in the social world happen as the result of human behaviour are seen as symbolic actions (Geertz, 2000). To untangle the complexity of those processes in their social world, ethnographic study provides methods that enable the researcher to engage in everyday life. These methods include: i) participant observation, ii) fieldwork, and iii) producing 'thick descriptions' of the social world lived in by the subjects (Rock, 2001, Geertz, 1973, p.6)).

Hence for the methodology, this study employs a focused ethnographic approach which flows directly from the symbolic interactionism perspective (Rock, 2001). Additionally, when focusing on family, Bomar defines family as:

"two or more persons who are linked together by intimate association, resources, and values and consider themselves to be a family" (Bomar 2004, p.9).

Another definition of a family, taken from the field of family medicine, is:

"a type of relationship generated by primary groups or groups of intimates with history and future" (Ransom, 1982, p. 64).

Bomar (2004) emphasises family members' links to each other, even though they may not have blood relationships; pointing out that the family members will share both resources and values. Thus, family members will affect each other because of these characteristics. Regarding the definition offered by Ransom (1982), it was stressed that a family has both history and future; meaning family members will always be tied to each other. It is reasonable to conclude that the members' previous experiences and shared values will shape their futures. Inevitably in a family, culture is shared and learned (Leininger, 2002). In families, the

older generation will inherit beliefs, values, and life-ways, and the younger generation learns their culture, as those beliefs and values are passed down to them (Leininger, 2002). Ethnographic study enables the researcher to spend an extended period looking into all aspects of a group's life, as its people go about their daily business, in order to gain a deeper understanding of their beliefs, values, and behaviours (Roper 2000).

This study used focused, rather than classical, ethnography because the extended participant observations of traditional ethnography were unlikely to be appropriate in this study. Those required observations may create an uncomfortable situation that could become intrusive and overwhelming for the families (Daly, 2007). Many families have and must keep their secrets that cannot be revealed to the outside world (Gabb, 2010). The participating families decided the best time(s) to visit their premises. During data collection, some families were very open to me (an outsider), but others were quite reserved. After the first meeting families that were very open emphasised that I could come to their house anytime. On the other hand, reserved families would ask me to call them first, or they would actually let me know of a convenient appointment time.

Even though this is a focused ethnographic study, with predefined questions, it is still informed by the principles of classical ethnography. These principles include: a) to study and understand human behaviour, especially the life-ways of individuals connected through group membership, b) to learn from people (family), and c) with the researcher being physically present in the real settings of the culture of interest (in this case, at the family's home) (Speziale and Carpenter, 1995). Using focused ethnography in studying a family's experiences in hypertension management helped me to gain an in-depth understanding of the family as an almost complete picture.

3.6 The study setting

This study was conducted in Denpasar, the capital of Bali. Bali is a province in Indonesia that is famous as a resort island. Denpasar consists of 4 sub-districts: North, East, West and South. Spradley (1980) highlights that seeking permission to gain entry to social situations can be a lengthy process, because of the complexity of some of the organisations involved. There were two layers I had to pass through in order to gain access to the families. The first layer involved participant recruitment at the Puskesmas (Community Health Centre). The second layer was gaining approval from the head of each household. At the first level, participant recruitment was conducted in 11 Puskesmas in Denpasar.

The gatekeepers at the Puskesmas ranged from the head of Puskesmas, the programme leaders, the physicians, and the nurses. Bryman (2004) suggests that gatekeepers could provide assistance to smooth the ethnographer's path in finding and dealing with situations, events and people in social settings. The majority of the gatekeepers guided me during the recruitment process; however, I faced some difficulties because the gatekeepers were too busy to help me. For example, physicians declined to help recruit patients. Rejections came not just from physicians but also from potential participants. Several possible participants declined to take part in my study for various reasons. Fortunately for me I had some acquaintances at the Puskesmas who gladly helped me in recruiting more patients, and who also explained my research to them. Making use of one's social circle is a tactic that can be very helpful in gaining access to potential participants; an initiative that proved successful in my case (Bryman, 2004).

The second stage of the permission-gaining process was at the family level. Gilgun, Daly et al. (1992, p.4) believe that family is the most private social group, because they are trying to hide their habits, rituals, and secrets from outsiders in an effort to maintain their unique self-definitions. The gatekeepers for this level include:

a) the head of the family, b) the patients and c) parents. Even though I approached the patients as they attended their clinic sessions, I still needed to seek permission from the head of the family. Once I had a situation in which I was attempting to recruit a young adult to participate, and he agreed to take part in my study. However, I could not include this family because his parents refused permission for their son to participate when I visited their house, and that is where that attempt ended. Parents are gatekeepers; in extended families I would need approval from the parents if I included their young children in the data collection process. During the data collection at Gatot's family, I could not include their grandchildren because their parents refused to participate in the research. It seemed the 'family issues' they were having at the time created a barrier to participation. At Agung's family, Sari did not allow her son to be included as a participant, because she believed he was too young.

3.7 Research participants

This part consists of explanations relating to: 1) the sampling strategy employed in this study, 2) the family as a study sample, 3) the inclusion criteria, and 4) the characteristics of the participants.

3.7.1 Sampling strategy

This study employed purposive sampling as the strategy to recruit the participants. Purposive sampling is the most convenient sampling strategy used in qualitative research, because it allows the researcher to select participants that are able to inform and understand the phenomenon being investigated (Creswell, 2008). The participants in this study are Indonesian families with one or more of their members identified with hypertension; with that member having agreed to take part in the study. The families were selected because they possessed particular

characteristics that enabled me to explore their experiences in hypertension control in daily life.

3.7.1.1 The families as study sample

“‘Family’ should be seen as topics to be explored further, in all their usages and ramifications, rather than as resources to be drawn upon uncritically”(Morgan, 1996, p.11)

Morgan’s quote implies the concept or term ‘family’ should be defined with sensitivity and care, to avoid losing the sense of fluidity and flux in a family. A family is not just ‘a thing’ but involves sets of practices performed by its members (Morgan, 1996).

3.7.1.2 Family

The definition of a nuclear family, as one that consists of father, mother and children, has been acknowledged and adopted in mostly Western societies and developed countries (Georgas, 2006). This small size of family in Western societies consist of two generations, but they are not totally isolated from their extended families (Georgas, 2006). The characteristic of nuclear family that is professed as ideal type of family values intergenerational independence, due to individuation-separation is essential for human development (Kagitcibasi, 2002). Kagitcibasi (2002) adds, interdependency between nuclear family and their extended family weaken especially in term of material because of better social welfare and affluence, but emotional (psychologically) interdependencies continue.

Meanwhile, in Indonesian society, the definition of family cannot and does not fit the Western nuclear model. First of all, this lack of fit is because extended family is prevalent in Indonesia (Utomo, 2016a), in extended families, material and emotional interdependencies are still prominent for family livelihood (Kagitcibasi, 2002). Furthermore, the lack of fit is because Indonesian society is complex, with multiple cultural dimensions, resulting in each ethnic group having their own taxonomy of what constitutes a family, as well as their own family-related terms

(Winarto, 2006). The mobilisation of people from one area to another in Indonesia has also helped to develop new definitions of 'family' among Indonesian society.

The government defines family as people who are listed in the family card, and refers as *KK* or *kepala keluarga* (translated as: the head of family). Those listed on the family card are people who live in the same house, and a group of people who live in that premises is called one *KK* (Winarto, 2006). However, the state's definition may not fit the term 'family' as it is used by various ethnic groups throughout Indonesia. For example, in Javanese society, 'family' refers not only to people who live in the same house, called *somah* (*se-umah* means one house) or *rumah tangga* (household), but also the term 'family' refers to relatives / kin (extended family), who may live far away from the house (Koentjaraningrat, 1985).

Meanwhile in Balinese society, the term family has a broad scope that primarily involves kinship customs. A household referred to as *kuren* is the nuclear family (Geertz, 1975, Belo, 1970). A *kuren* usually lives with several other *kuren* in a houseyard, although sometimes a household consists of only one *kuren*, where this *kuren* will all share a kitchen and food supply (Geertz, 1975). A house yard group is organised around paternally related kinsmen, and it is the primary group for the Balinese, where they have intimate and enduring relationships with the other members (Geertz, 1975). The irregular pattern of Balinese kinship is because, in addition to kinship in the domestic domain, Balinese are also tied to kinship in the public domain or *dadia*. The *dadia* is a fully corporate kin-group, and it is considered as family because the members engage in private worship at the shrine of their common origin within the houseyard of one from among them (Geertz, 1975).

Family is also developed as the result of urbanisation in Indonesia. People from one area move to big cities and they develop a group consisting of people from the same original home area. Such a group will be referred to by its members' kin

(*kerabat*) (Equanti and Bayuardi, 2016, Malik, 2016). The background of the group's formation is, first of all, to help those who have just arrived in the new place, to adapt to the new place smoothly, and secondly it is formed in an effort to preserve their original cultures and values (Rajab, 2004, Equanti and Bayuardi, 2016). Because of their similar cultural and religious backgrounds the people from the same area become very close and consider the group as a family.

3.7.1.3 Family in this study

As demonstrated above, defining 'family' within Indonesian society is extremely complex and involves a very wide circle, which may not be appropriate for the purpose of this study. Therefore I will not apply any of the aforementioned family definitions to define family in this research. My definition of 'family' as a unit will include the patients and other individuals who are involved in the interactions related to caring for the patients. Those patients and individuals are connected by blood, as well as marital and /or other forms of relationships with the patients, and who support each other for emotional, physical and economical need fulfilment.

3.7.2 Participant inclusion and exclusion criteria

Inclusion and exclusion criteria predefine the eligibility of a participant subject in the research study (Salkind, 2010). For this study the inclusion criteria is set for hypertensive patients and their families.

3.7.2.1 Patients' inclusion and exclusion criteria

The patients' inclusion criteria include being identified with hypertension, and without any other chronic diseases. Hypertension and other chronic disease management will require different interventions; in addition, the patients may prioritise one disease over another (Anthony et al., 2012). Therefore, focusing on patients who only have hypertension is expected to minimise any bias resulting from

patients' priorities in controlling their diseases. However, the exclusion criteria include patients with severe hypertension. This criterion is set to prevent any adverse impact as a result of joining this study's participant population.

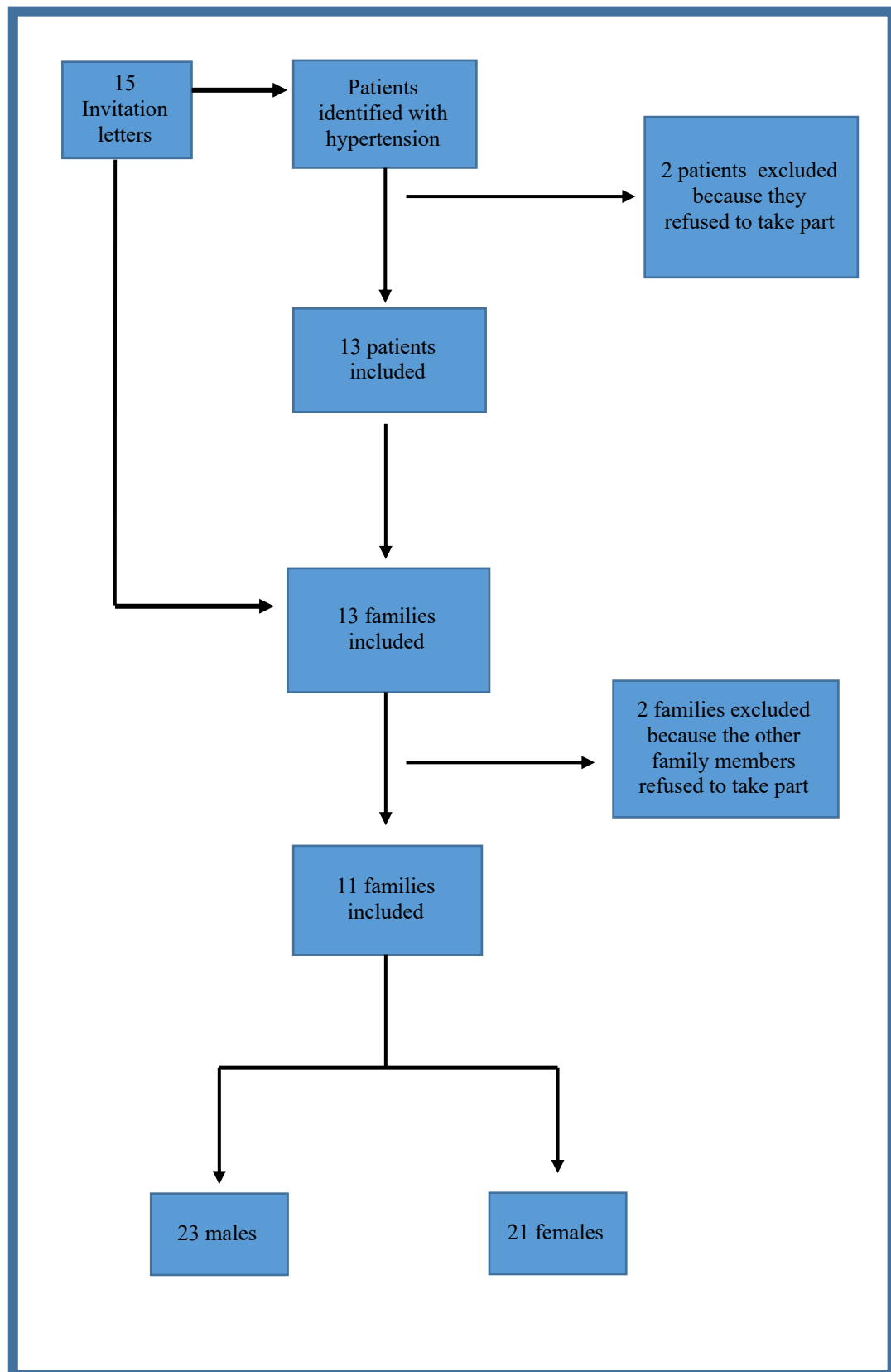
3.7.2.2 Families' inclusion and exclusion criteria

The families were included in this study if they agreed to take part and gave approval for me to visit their homes. As described above I firstly approached patients in the clinics to get their permission to access the family domain. However, I also recognised the possibility that other family members might decline to take part in the study. The exclusion criterion for the families was simple; anyone asking to terminate their involvement in the study was automatically excluded.

3.7.2.3 The process of recruitment

I included 11 families with a total of 44 family members: 23 males and 21 females. The recruitment stages at the clinic are presented in figure 1.

Figure 1: The recruitment stages at clinics



The details of family members are presented in Table 3 (page 106). Following approval from the School of Health in Social Science Ethics Research Committee at the University of Edinburgh (see Appendix 1) and the Ethics Committee of the Ministry of Health, Indonesia (see Appendix 2), I began recruiting the patients from Puskesmas located in Denpasar, Bali. The nurses and doctors in Puskesmas assisted me in recruiting the potential participants.

I explained to the staff my inclusion criteria that the patients must not have other chronic conditions, such as dementia or other mental health disorders, nor cardiovascular diseases, endocrine and metabolism disorders. Neither should potential participants be suffering from any severe muscular-skeletal disorders. Such conditions might prevent hypertension control as a priority of care. Even though the patients that I recruited were all suffering from hypertension, the medical staff could not guarantee if other conditions, such as declining renal function, had developed because there was no advanced examination available at the Puskesmas that could detect such conditions.

When I could approach the patients, and they indicated willingness to have conversation with me, I would ask their permission to visit them at their premises. On the first visit, I mostly met the family members identified with hypertension, who acted as the family's spokesperson; also I would meet the patients and their spouse, or the patients with their children. I explained my research to them and asked them to communicate my study to other family members. I always emphasised to the patients and their family that the participation in this research was voluntary and they had the right to refuse and/or withdraw their participation at any time. On the second visit to each family, I obtained their decision and started my observations straightaway if they agreed to participate. For this study the inclusion criteria involved adult family members and children older than nine years of age.

3.7.2.4 Patients

There were 12 patients in the study: nine male and three female. The youngest patient was 52 years old and the oldest 73 years old; all were having medication to control their blood pressure. Their roles in the family included husband, father, grandfather, wife, mother, and grandmother. All patients were visiting Puskesmas to have their regular blood pressure checks, to obtain their medication and / or to attend the weekly gymnastic session. There were 50% who regularly attended the gymnastic sessions, while the rest only attended the Puskesmas for their regular checkups and to receive their medication.

3.7.2.5 Families included in this study

There were five nuclear families and six extended families that participated in this study. Pak Agung's family had the most family members (7) who took part in this study, because two nuclear families shared the house. I also interviewed family members that lived in different houses, because they played significant roles in a patient's daily life. I interviewed Pak Gatot's son, who lived nearby because the son took the primary responsibility in caring for his parents. I actually should have included Pak Gatot's daughter who lived in the house, but she declined to take part in this study because of family issues. I also interviewed Pak Sadu's daughters, who lived in different houses, because Pak Sadu and his wife visiting their daughters almost every day, or *vice versa*. So, they meet each other nearly every day and therefore I thought it important to include them in this study.

3.7.2.6 Family members

Family members included in this study, in addition to the patient, were: spouse, daughters, sons, daughter in laws, son in laws, granddaughter, grandsons and non-blood family members. 'Non-blood family members' refers to people who

live in the same house, but who are not blood relatives to the patient. For example in Pak Joko's family, three 'family members' lived with the couple. These 'family members' do not have any blood relation with the couple, but they do have close relation with Pak Joko and his wife. Wimar's family employed a servant who had already become part of their family. One family considered their pet as a family member, so I included the dog in the genogram, but gathered the information about it from the owner. Pak Sadu and Bu Marni told me their dog is their alarm in the morning and referred to it as a 'family member'. The dog also took part in Pak Sadu's physical exercise. The list of family members is presented in Table 3.

Table 3: Family members and type of interview they attended

NO	FAMILY PSEUDONYM	NUMBER OF FAMILY MEMBERS WHO PARTICIPATED	FAMILY MEMBERS WHO PARTICIPATED	AGE	GENDER		FAMILY INTERVIEW	ATTENDED DYAD INTERVIEW	INDIVIDUAL INTERVIEW
					Male	Female			
1	Dony's family	2	Pak Dony (Father/Patient) Dina (Daughter)	62 16	1	1		Dony and Dina	-
2	Joko's family	5	Pak Joko (Patient/Husban) Bu Rena (Wife) Bima (Relative) Sena (Relative) Arya (Relative)	52 51 24 23 23	3	1		Pak Joko and Bu Rena	Arya, Bima, and Sena
3.	Agung's family	6	Pak Agung (Father/Patient) Raka (Son) Yoga (Son) Rina (Daughter in law) Sari (Daughter in law) Eka (Grandson)	73 38 34 30 34 17	4	2		Pak Agung and Sari	Raka, Yoga, Rina and Eka
4.	Wimar's family	5	Pak Wimar (Father/patient)	65	1	4	Pak Wimar, Bu Puri, Rita		Rumi

			Bu Puri (mother) Rita (Daughter) Rumi (Daughter) Mona (Relative)	53 30 23 50			and Mona		
5	Gatot's family	3	Pak Gatot (Father) Bu Lely (Mother/Patient) Karno (Son)	72 63 42	2	1		Bu Lely and Pak Gatot	Karno
6	Sadu's family	4	Pak Sadu (Father/Patient) Bu Marni (Mother) Mia (daughter) Eli (Daughter)	67 63 41 37	1	3		Pak Sadu and Bu Marni	Mia , Eli
7	Jono's family	4	Pak Jono (Father/patient) Bu Karti (mother) Mila (daughter) Arman (grandson)	71 67 42 9	2	2	Pak Jono, Bu Karti, Mila and Arman		Karti
8	Hendra's family	4	Pak Hendra (Father/Patient) Bu Maya (mother) Wina (Daughter)	67 54 33	2	2		1. Pak Hendra, Bu Maya 2. Wina and Gama	

			Gama (son in law)	33					
9	Kanda's family	7	Pak Kanda (father/patient)	66	4	3	Pak Kanda, Bu Dinda, Jepun, Adelia, Bona and Verdy		Jati
			Bu Dinda (Mother)	65					
			Jepun (daughter)	40					
			Jati (son in law)	41					
			Adelia (grand daughter)	17					
			Bona (Grandson)	12					
			Verdy (Grandson)	11					
10	Hadi's family	2	Pak Hadi (Father/patient)	60	1	1		Pak Hadi and Bu Tari	
			Bu Tari (Mother/patient)	60					
11	Dago's family	2	Pak Dago (Father)	61	1	1		Pak Dago and Bu Siwi	
			Bu Siwi (Mother/patient)	60					
	TOTAL NUMBER	44			23	21	3	9	13
	TOTAL INTERVIEWS						25		

3.7.2.7 Gender distribution

Hypertension is more prevalent in men than women for middle age groups, but the number increases in women older than 59 years (Lloyd-Jones, 2018, August, 2013). For this study I recruited 10 patients aged over 59 years and only 1 patient who was less than 59 years. As for the gender distribution, I recruited 9 male patients and 3 female. Even though statistically more women are affected by hypertension for age group >59 years old, I found it difficult to recruit female patients. The situation is slightly different to a study conducted by Markanday et al. (2013) who noted the number of men declining their research invitation was greater than women. The main reason for men refusing to take part in research, according to Markanday was that men do not have enough time to take part. While for women, they decline the invitation because they do not understand the study, or they do not want to take part in medically-related research.

In this study, the reasons given by female patients for declining their research invitation were: i) they were not interested, ii) they did not have enough time, and iii) they did not live with their family. This situation was slightly different to the one studied by Markanday et al. (2013). There were four women who declining my research invitation. The first lady I met was in her late sixties, and came to Puskesmas to have her regular blood pressure check and to obtain her medication. The male nurse told me to approach her but seemed unsure if this lady would agree to take part, but he told me to try; therefore, I approached her to explain my study. However, before I was able to finish my explanation she said it is impossible for her to take part because she does not live with her family, but with her employer's family. She had worked as a maid for 'her family' for such a long time she did not want to upset her employer by taking part in this study. She thought her participation may create an uncomfortable situation for the employer's family. The second female

patient I met was in her forties. I met her during the weekly gymnastic activity in her Puskesmas. Once the nurse, who was the coordinator for this activity, had told her about my study, I then approached her. She agreed to participate even though I could see that she was not too sure about it, but she invited me to meet her family at her house eventually. I went there on the date we agreed on, and it was slightly challenging to find their address. Finally I met her husband and daughter, they were very friendly family. They served me a cup of tea and cakes. I then started to explain my study to them, but unfortunately this family did not want to participate. The husband said he probably will not be at home most of the time because of his working hours. The wife also said she could not take part in this study because she would be busy running their small shop. The other two women declined because they were not interested; they refused even before I had the chance to explain my study to them.

Also, there were two male patients who did not want to take part in the study. The first patient was a young man in his early twenties. At first he agreed to take part but his parents declined to get involved because they would not have time to meet me when I visited. The parents owned a shop that was located far from their house. The second man refused to take part in my study because previously he took part in some activities conducted by nursing students. I assumed he was recruited as a case study during an internship and he possibly thought I would involve him in the same activities.

It is quite possible that females and males will have different reasons for taking part in a study. The study conducted by Markanday et al. (2013) mainly examined the reasons of individual participants for not taking part in health studies; whereas in my study the participants included not just the patients but their family members as well. Therefore, there must be other reasons that could affect their participation in this research. Newington and Metcalfe (2014) suggested the

recruiter's personal characteristics, and the nature of the study, also influence potential participants to accept or decline a research invitation. The nature of my research may have been perceived as too intrusive for some potential participants, as the research included the family members as participants, and the researcher would be observing a family's life in their own house. Other than the nature of the research itself, the issue of the recruiter's characteristics is noteworthy. For this study some health staff helped me with the recruitment. Newington and Metcalfe (2014) added that potential participants would be more likely agree to take part in a study if they were asked by their doctor, or someone else they trusted. However, I was a complete stranger to the patients, which could have biased them towards rejecting my invitation to participate.

3.8 Data collection

To gather information about the participating family members I employed observations and interviews. Details of these methods begin with a description of family visits, followed by explanations of observations and interviews.

3.8.1 Visiting the family

In this section I explain the time arrangement for the visits and the patients as the gatekeeper.

3.8.1.1 Time arrangements

The family is a group that has been known for its mostly closed and private characteristics, which preserve and protect its activities and processes in order to maintain their *unique self-definitions* (Gilgun et al., 1992). Gilgun and colleagues added that a qualitative study approach to information gathering requires the researcher to build trust and rapport, if he or she is to access the family's private sphere. My first priority was to respect their decision for the timing of home visiting.

Each family is unique; they had different preferences for the timing of my visits. They also decided the duration of my visits to their houses. There were two families who let me visit them at anytime, but the other families allocated 1-2 hours for each visit. We agreed to start the visits after lunch, but the longer the relationship the more flexible they became. For example, there were families which gave permission for me to visit them early in the morning. However, there were other families that were less flexible and only allowed visits of 1 hour.

3.8.1.2 The patients as the gatekeepers

Silverman (2013) divided research settings into 'closed' or 'private' and 'open' or 'public', depending on the availability of access into the setting. Informed by those two types of research settings, the family is 'closed' or 'private'; an entity which cannot be accessed freely, and with that access being controlled by the gatekeepers. In my situation to gain access into the families, the patients were the gatekeepers; whereas access to the patients was controlled by the physicians and nurses in the Puskesmas, in their gatekeeper roles.

The first contact I made was with the patients. On my first meeting I explained my study, which would require me to meet the other family members too. On my first house visit the patient-gatekeeper would call the other family members and introduce me to them. The patients also arranged my meetings with family members who do not live in the same house as the patients. The patients explained to me the family members' availability at home; so I could make plans to visit them.

3.8.2 Participant observation

This section discusses the information gathering method of participant observation, presenting three areas of importance: 1) the introduction, 2) the observation process and 3) the observation notes.

3.8.2.1 Introduction

Participant observations are one of the core features in ethnographic research (Spradley, 1979, Hammersley, 2010, Atkinson et al., 2007). Participant observation occurs with the aim of an observer or observers being located in a certain natural setting in order to experience the social life and social process taking place in that setting (Atkinson et al., 2007). I started conducting the observations directly, once the family had agreed to take part in the research. That was a strategy to familiarise myself with the social phenomena experienced by the participants. Overt observations took place at the families' premises, Puskesmas, public park, crematorium, and *banjar*. Due to the study's overt observation design, my field role was both participant-as-observer and observer-as-participant. Hammersley (2010) suggests that a researcher should take the role as a complete *bona fide* participant when the research is concealed, or the researcher is already a member of an organisation. Meanwhile, Hammersley (2010) added that the 'complete observation is possible to be conducted when the researcher's role does not need any contact with the participants, for example conducting observation in public setting such as observing people behaviour on the street. Meanwhile for this study, I have to make contact with the family members, a situation in which it was impossible to conduct covert research; thus both my roles were in play, depending on the requirement at the study setting.

It was impossible to stay at the families' premises for any excessively long period of time. The first reason for this limitation was the families set the time I could come to them and the duration I could stay at their premises; so observations ranged from 1 to 3 hours. Due to the very limited time for the observations, I mainly had informal conversations with the family members who were available at the time I visited their premises. This role aligned with Lofland (1972), who suggested

participant observation involves three activities: i) watching, ii) listening and iii) asking.

It is likely that the degree of involvement, and type of participation, will affect the insider/outsider experience of the researcher and, in turn, influence the style of conducting that research (Spradley, 1979). The level of participation will depend on the natural settings that are being studied. However, maintaining the balance between insider and outsider experience may enhance the understanding of an event, because there will be an opportunity for the researcher to validate the observation results when she/he becomes the participant (Roper, 2000; Spradley, 1979). I had some chances to take part in families' activities as well as the patients' activities. One of the families invited me to come to their family gathering, and they asked me to help them with the meal preparation. They also introduced me to their relatives. This activity gave me the experience of being a family member.

Spradley (1980) divided observation into: i) descriptive, ii) focused and iii) selective. 'Descriptive' observation is an observation to obtain the general features of social settings. During this observation, the issue of 'what is going on here?' is covered; especially in the beginning of my interactions with the families. 'Focused' observations were employed when participants conducted specific activities, such as family members' interactions at home and regular physical activities. These focused observations then lead into 'selective' observations in which each specific activity was compared between the families. These three kinds of observations were employed flexibly, depending on the situation in the natural settings. The Friedman Family Assessment Model (FFAM) (Friedman et al., 2003) guided the observation process; the *genogram* and *ecomap* instruments are also used in the observation process. An explanation of the FFAM model is offered in the following section.

3.8.2.2 Friedman Family Assessment Model (FFAM)

The FFAM is an assessment model used during observations to gather information about the families. The FFAM was used for this study because it utilises general system theory, cross-cultural approach, and communication theory (Friedman, 2003); a combination approach that is compatible with general system theory, cybernetics, and ethnographic study, all of which inform this study.

The FFAM consists of six categories: 1) identifying data, 2) developmental stage and history of family, 3) environmental data, 4) family structure, 5) family functions, and 6) family stress, coping and adaptation.

Friedman (2003) emphasises that assessment of subcategories is dependent on the family's goals, problems and resources; thus assessing all areas is not necessary and hence redundancy is avoided. Based on Friedman's note, this study aims to scrutinise the family's experiences in hypertension control. Therefore, my assessment mainly focuses on answering the research questions that were relevant to the families that I studied. Therefore, Friedman's six categories were applied to meet the needs of this study, which were to gather data related to hypertension control within a family environment. The categories utilised for observation in this study were developed predominantly in accordance with the family conditions within their Indonesian cultural context. Friedman's concept in family nursing was mainly grounded in the Asian American family context; a situation in which the Asian culture had experienced acculturation by the Western culture of North America. Consequently there might be areas that were not covered in the assessment form; areas that might be of significance when trying to describe the family in an Indonesian context. Therefore, the six categories used in this current research mainly followed the situation of the family, rather than strictly following the original version of the FFAM. Please see Appendix 14 for the observation guidelines.

3.8.2.2.1 Identifying data

The first category of FFAM describes the family details, which include: 1) family name, 2) their address and phone number, 3) family composition (genogram), 4) type of family form, 5) cultural background, and 6) religious identification. I would include the family's name and composition on the genogram for each family. A genogram is a useful tool to identify a family's composition, as it enables the inclusion not only of the household inhabitant members, and blood related members, but also non-household inhabitants, extended family members and other people that are also considered as part of the family (McGoldrick, 2008, Wright and Leahey, 2013, Friedman et al., 2003). However, it was not just humans who were family members; some households considered their pets as family members too. Cain (1985) has studied whether pets can be considered as family members or not, and the study found most of the family members considered their pets as full family members. Pets were seen as very important for the family, having contributed to the quality of family life in many positive ways. Other than Cain (1985), another study conducted by Cohen (2002), suggested pets are identified as family members by the way in which pets function within the household. For this study, pets are included in the genogram, if the families considered them as their members.

Historically, the traditional nuclear and extended family forms have shaped families in Asia. However, due to social, economic and demographic changes, family forms have experienced many transformations that have resulted in a range of different family shapes and sizes (Dommaraju and Tan, 2014, Quah, 2008). Friedman (2003) categorised three major family forms that are relevant to major populations: 1) nuclear family, 2) extended family and 3) single-parent family. Macklin (1987) had earlier developed alternative family forms, such as an augmented family, that is a family form consists of nuclear family with one or more unrelated persons. This study adopted both the major and alternative family forms

suggested by Friedman (2003) and Macklin (1980). The issues of a family's form and family members' connections have been presented in the above section.

The social class sub-category mainly assessed the economic status of the family. Economic status is seen as an important determinant of health (Marmot and Wilkinson, 2006); the economic status challenges to hypertension control are presented in this section.

Cultural background is an important variable in family care (Friedman, 2003). Leininger (1978) suggested that ignoring patients' sociocultural factors results in inadequate care that consequently prolongs the care process and prevents treatment goals from being achieved in timely fashion. To answer the research questions, the assessment of cultural backgrounds focused on cultural practices that influence hypertension control in daily life, such as dietary habits, and other religious and community practices, are presented in this section.

3.8.2.2.2 Developmental stage

Friedman formulates this category to assess the family's present developmental stage and whether they have fulfilled the tasks appropriate for their present stage. However, this issue may not be directly relevant when posing the current research questions. Therefore, the developmental stage section in this study covers the family's development in its attempts at controlling its member's hypertension. Families' experiences of controlling hypertension from the beginning, their current experiences and future challenges have been presented in this section.

3.8.2.2.3 Environmental data

Related environmental data that facilitate or prevent the families controlling hypertension are discussed in this category. The families' and patients' awareness of public amenities and services that facilitate hypertension control is discussed.

Whether those facilities are adequate for the families to support their hypertension control efforts is an important issue that is also examined in this section.

3.8.2.2.4 Family structure

Friedman (2003) suggests the family structure category observes a family as a whole, through their communication patterns. In this study, the category presents the way family members related to each other, in terms of their hypertension control practices, by focusing on who has the power in the family for making decisions regarding hypertension control-related activities.

3.8.2.2.5 Family functions

This section focuses on health care functions carried out by the family; specifically in the context of hypertension control. The families' knowledge and perception regarding the issue of hypertension, the roles of the family in daily hypertension control and the family's awareness regarding hypertension are presented in a reflective way.

3.8.2.2.6 Emotional expression and family response strategies

Family stress, coping and adaptation form the last category that needs assessment in the FFAM. Stress and coping are parts of emotion (Lazarus, 1999). As the super-ordinate concept, emotion covers a wide range of mental states including anger, anxiety, stress, happiness, sadness and depression (Lazarus, 1999, Cabanac, 2002). Increased levels of emotion, particularly stress, can significantly raise an individual's blood pressure (James et al., 1986). Assessing the family's response strategies to emotional expression provides important information about behaviours and communications relevant to hypertension management. Rosland et al. (2012) studied family responses to illness management, noting they were associated with self-management outcomes. An attentive environment informed by family cohesion results in better patient outcomes, when compared to

critical, negative and distracting family responses. Emotional expression, and its impact on family response strategies are the aspect of family that will be presented to cover family's stress, coping and adaptation (the original category of FFAM assessment).

3.8.2.3 Genogram

The genogram concept is employed in this study to understand various patterns within a family; for example: how, over time, a health problem evolves in the context of a family. Genograms provide information relating to the family members and their relationships. Therefore, we can gain information about the family structure and the patterns of relationships and functioning spanning at least three generations (McGoldrick, 2008). A genogram is also an important feature to describe a family with chronic conditions, such as hypertension, where the condition's cause is potentially, if not certainly, related to the patient's behaviour patterns. The genogram provides information about intergenerational past patterns of behaviour that would be relevant to visualising the family as a system (Taylor et al., 2013). Not only is the genogram an assessment tool, it also visualises the family members' relationships (McGoldrick, 2008). In addition, it can also be employed as a therapeutic tool that helps the individuals and the family to reflect upon the ways their current and past generational patterns have influenced the formation of their current family picture (Duba et al., 2009). This study employed the genogram envisaged by McGoldrick (2008), using the basic symbols to assess the family's compositions that consist of information about: i) family members' current conditions, and ii) their relationships. The genograms were constructed after the initial meetings and revised by me as new information became available. The symbols used in the genograms are presented in the section dealing with family profiles in Chapter 4 (page 167).

3.8.2.4 The ecomap

In addition to the genogram, this study also presents the data of family via an ecomap format. An ecomap is a visual illustration of a family's existential relationship with the environment (Hartman, 1995). It consists of information about a family system's connections with various environmental systems or domains; for example: 1) school, 2) health care facilities, 3) kin, 4) work, 5) recreation and 6) temples. The ecomap's role in research has been extensively documented as useful and rich in providing information that the genogram does not cover (Hodge, 2000, Ray and Street, 2005, Yanicki, 2005, Leahey and Wright, 1987b). For example, the ecomap would provide information about the external sources of support in family caregiving, and the changing support available for the family; whereas the genogram would show only a stable situation within the family at that same time (Rempel et al., 2007). In the ecomap the family is placed at the centre, and every other domain, such as kin, person, organisations and institutions, should be named and placed in the outer circle. The domains themselves are connected by different types of lines, which represent the strengths of the relational connections. According to Hartman (1995) the basic symbols in the ecomap, designed to show connections between the family and external environment, consist of simple lines of different thicknesses, broken lines, and arrows. The thicker lines represent strong and healthy connections between the family and the external source. Broken or 'lightning' lines represent a stressful connection between the family and other domains. An arrow pointing to the family means the family is influenced by the external environment, and *vice versa*. The arrow pointing in both directions means there is reciprocal connection between the family and external factors. In this current study only the external environment that influences the family's hypertension control is presented. The components of the external environment included in this study

involve both physical facilities and social networks. The ecomap symbols used in this study are pictured in the family profiles, as presented in Chapter 4.

3.8.2.5 The process of observation

The research observations began with my first visit to a family's house. During the first visit I gathered information about the family, which included the family's composition (drawing the genogram), type of family, the family's developmental stage, ethnic and religious backgrounds, their social class and the environment. I captured some important information from some families related to family dynamics when the genogram was drawn. I could see the communication and interactions between family members. During the first visit to Sadu's family, we drew the genogram together: me, Pak Sadu and Bu Marni. The communication between this couple was effective, and they supported each other. Pak Sadu sometimes gave wrong information, but then Bu Marni would correct her husband, and *vice versa*. The couple received and gave feedback from and for each other. I focused the observations on the environment, in order to capture the families' accessibility to public amenities. For example, what was the distance from their house to the clinic and park; issues which probably could affect their motivation for controlling their blood pressure.

Communication problems were witnessed in Agung's family. On my later visits to Pak Agung's house I noticed that one of his sons never got involved in any conversations when I visited their house. He never wanted to join the conversation. Later I found that Pak Agung's sons cannot get along with each other, because one of them admitted that he cannot stand the way his brother tries to communicate with him.

Women took the major roles in housework, such as cooking, childcare and caregiving. The women's main role in cooking that I witnessed was in one visit to

Wimar's family; Pak Wimar complained to his wife because the vegetables she had cooked were too oily. This example shows if women have more control in preparing foods in Pak Wimar's family.

In the matter of childcare, both mothers and grandmothers took care of the children. The grandmothers, such as Bu Karti, Bu Siwi, Bu Lely, were responsible for taking care of the grandchildren when their mothers had to work. As with many families worldwide, the mothers would take over when they finished their office hours.

Women also made greater efforts in trying to keep up the standards of their family members' health, when compared to the male members. Pak Sadu and Bu Marni both have a strong will to maintain their health, but Bu Marni was the one who always reminded her husband to control his blood pressure and make sure that they take their medication regularly. She told me that they used to ignore their medications, but since they attended the weekly activities at the clinic, they decided to change their ways. They now take their medication regularly, and it was Bu Marni who prepared all the medication for both of them. She moved all the medications to a more visible place, so they would remember to take them.

I also requested to observe certain activities, such as food preparation and the patients' exercise activities. The patients sometimes invited me to get involved in their social activities, such as family gatherings, festive days and wedding receptions. As a result I was privileged to be able to observe their interactions with their peers, relatives and their neighbours. One time Bu Lely invited me to come in the morning to see the way she prepared the family's daily meals. I also helped her to prepare the ingredients and fry the foods. The meals were mostly fried because she said the children loved such food; equally there were no special meals for her or her husband.

During the interviews I also noted interesting situations. I met some family members that I had not met before, so I could see their interactions with other family members. During the interview with Pak Hendra's family, I witnessed interaction between Pak Hendra and his wife, and there was a distance between them. There was a moment that confirmed the distance, when Bu Maya became quite emotional because she never knew how her husband managed his stress. She showed guilt over that and she cried. It seemed this family kept secrets from each other.

3.8.2.6 The observation notes

Exploring a certain social phenomenon in its natural setting is one of the main characteristics of ethnographic study (Spradley, 1980, Hammersley, 2010). The researcher builds up ongoing relationships with the people in those settings and observes their daily lives. As a result of these initiatives, the accumulation of observations that the researcher experienced is recorded in written form or as fieldnotes (Emerson, 2011). The fieldnotes represent a 'close proximity' to natural settings and selectively present certain phenomena that are significant for the researcher (Atkinson et al., 2007).

The notes in my study were mostly taken after a house visit. I could not take proper notes during the conversations because it was obtrusive, somewhat rude and stopped the conversation. The notes were written in two phases. The first phase was right after I left the participant's house; mostly I stopped at the nearest food stalls and elaborated any words I had jotted down during my conversation with the family members. In the second phase I refined the notes at home and started to analyse the points made. I could not write the respondents exact sentences; therefore, I summarised what they had said.

I wrote fieldnotes in descriptive form for each family. Fieldnotes for a family consist of family details, including: 1) the cultural background and genogram, 2)

environment, 3) affective function of the family, 4) family health care function, 5) family economic status, and 6) the interaction and communication between family members. Whenever possible, notes were also taken during the interviews. The focus was more about the interactions, body language and emotions that were shown by the family members. However, due to my limited interaction with some families, the fieldnotes from such families may not be of the same quality as the notes from the other more 'open' families.

3.8.3 Interviews

3.8.3.1 Introduction

Qualitative interviewing is a research method that enables the interviewer to gain information and descriptions of the interviewee's worlds of life and work, as well as exploring specific situations, experiences or events (Rubin & Rubin, 1995). Interviews ensure achievement of depth and breadth of understanding in certain areas. A comprehensive outcome is impossible to achieve using standardised questions in a questionnaire, as such an information gathering approach will also lead to standardised answers that are likely to provide only a superficial understanding of the issue or issues in question (Mason, 2002). In focused ethnography, it is possible to conduct various forms of interviews to gain a large amount of data in a relatively short period (Knoblauch, 2005). Spradley (1980) suggested there are two types of interviews in ethnographic studies: informal and formal. This current study employs both informal and formal interviews. For the formal interviews I used semi-structured models, with open-ended questions as the method of data collection. Semi-structured interviews help in obtaining relevant information, as their design guides participants to focus on aspects of experience that are related to them. Charmaz (2014) explains that interview guide could prevent

a researcher from asking the wrong questions; but sometimes interview guidelines in turn could lead to a failure to explore important issues if it is strictly followed. Intensive strategies guide the interview which will allow participants to share their experiences, how they portray those experiences and whether the experiences have meaning to them and, if so, what they mean to the respondents (Charmaz, 2014). An interview guideline was developed to facilitate the semi-structured interviews that took place in this research. The guideline consisted of 12 questions, the development of semi-structured interview guidelines is elaborated in section 3.8.3.2. For the interview guideline please see Appendix 13. The formal interviews were recorded using a voice recorder, and transcribed as soon as possible after the interview had taken place.

An informal interview is one that occurs during participant observation; it does not need a prior appointment for it to take place. However, with a formal interview the researcher needs to request a specific time to hold the interview. Informal interviews mainly involve casual conversations between researchers and participants. Such interviews are mostly conducted at the initial stage of data collection, prior to any scheduled formal interviews. Spradley (1979) suggested casual and friendly conversations can yield a significant amount of data. It was also suggested that such a format manages to make the interview appear less like a formal interrogation; a perceived format which could frighten the participants, especially during the initial phase of fieldwork. As Fraenkel (2006) suggested, casual conversations before joint family interviews were needed, so allowing families to feel more comfortable and intimate in telling their experiences. With family members as participants, this current study employed group, dyadic and individual interviews. In the following sections, the development of interview guidelines, interview approaches, and what they involve, are discussed.

3.8.3.2 The development of interview guidelines

This study utilised interviews as one method of data collection. Interviewing is a legitimate way to generate data to understand people's experiences or to gain knowledge about a certain topic. Mason (2002) suggests people's experiences and understanding of certain events in their daily lives can only be constructed and reconstructed in interviews. Further, during the interview process the interviewee is encouraged to show their capacity to verbalise, interact, conceptualise and remember.

A semi-structured interview utilises a set of open-ended questions that encourages participants' spontaneous and in-depth responses (Ryan et al., 2009). The development of semi-structured interview guide begins by conducting a literature review in order to reveal evidence of families' involvement in hypertension control. Kallio et al. (2016) suggest retrieving and utilising previous knowledge in developing semi-structured interview questions is crucial to gain a comprehensive and adequate understanding of the subject being investigated. Mason (2002, p.69) argues that developing interview questions starts with a 'big question', a question that can and does inform the way the study is conducted. In this current study the 'big question is "how do families experience managing hypertension in daily life?" This big question was then expanded into 'mini questions' and these mini questions linked the big question to its subcategories (Mason, 2002).

The big question yielded three mini questions; the first being a broad question about hypertension. Ryan et al. (2009) suggest a broad and guiding question trigger participants' descriptive response and stories. This broad question about hypertension was then expanded to gain understanding about the family's perceptions and knowledge related to causes, preventions and treatments of hypertension. The second mini question focused on the family's involvement in daily hypertension control, which embraced the general aim of this current study. The

third mini question was about the barriers and facilitators influencing hypertension management. The family's involvement, barriers and facilitators in hypertension control are issues that yield the most appropriate questions to explore a family's experiences in hypertension management. Information about the implementation of certain strategies in chronic disease management, and the problems experienced during the process, need to be identified in order to find approaches for improving chronic illness care (Burt et al., 2014). The mini questions should be asked in a flexible non-rigid format, in order to avoid any impression that the researcher is leading the discussion, rather than facilitating and encouraging the participants to describe their experiences (Speziale and Carpenter, 1995). In addition, prompts or probes were used to encourage respondents to expand their answers, or to redirect them to the main topic if they drifting off target (Ryan et al., 2009). Please refer to appendix 13 for the interview guideline.

3.8.3.3 The interviews

The following paragraphs describe three types of interviews conducted for this study. The first is the family interview, followed by a dyadic interview and individual interviews. All interviews were conducted at the participants' houses and were recorded. I made appointments with all the family members prior to the interviews and ensured their availability a day before the interview date. This 'safety call' was in case they had other situations that caused them cancel the arranged interview. Before I started the interview I again briefly explained the purpose of the interview, that the interview would be recorded and that any interviewee was welcome to ask questions before we began.

3.8.3.3.1 Family interviews

This study employed family interviews to obtain information from the family members. The family interview is an interview approach when all the family

members are interviewed together, at the same time (Couch, 1969). Gathering the whole family together for an interview provides details of the broader family dynamics, due to their complexity and interdependence throughout the life course (Reczek, 2014). I conducted family interviews with 3 families. The family interview was conducted when more than two family members at the house joined the interview. The interviews lasted from 40 minutes to 1 hour.

I did not arrange the seating of family members during the interviews, because I had to adjust to the spaces available in their house. The advantages I obtained from conducting family interviews were that I could capture the family's discussion about hypertension; behaviour I would not have witnessed during the observation sessions. Åstedt-Kurki and Hopia (1996) mentioned that family members would share their experiences easily because they share daily experiences which then build emotional bonds among them. The need for me to capture more emotional bonds through experience sharing was another reason I avoided arranging the seating during the family interview.

The main aim of a family interview is to gain information about what the family members were saying together, rather than looking at who was actually speaking about the issue (Åstedt-Kurki and Hopia, 1996). During the interview I witnessed family members were relaxed enough to quite easily complete each others' stories. For example, in Kanda's family Pak Kanda did not take his medication regularly; he only took medication when he felt or thought he needed it. His daughter supported his statement by saying that medication is poisonous, it could have a negative effect on the human body, including her father's.

Family interviews also enabled me to meet some family members that I rarely saw. I had never seen Pak Wimar's daughters around the house when I visited, prior to the family interview. I finally met one of them on the interview date. I took this opportunity to gather information about the family's daily routines, to complete the

notes for this family. I started the interview by asking whether everybody knew that one of their family members was suffering from hypertension. This enquiry was followed by questions for young family members that were created using very simple words. Whilst a family interview is an efficient way to obtain information related to family dynamics, conducting such an interview is very challenging. Gathering all family members at the same time proved extremely difficult; some family members were not in the house during the interview, even though we had all agreed for the interview to take place. The other reason for this format being so challenging was because, when a family had issues about communicating with each other, they would implicitly refuse to attend the interview; they would just not be there. The family interview was also very tricky when there were young family members around. Some of them played with the voice recorder, cried, shouted, and looked for attention from the parents and grandparents; all of which resulted in interview interruptions. Some of them watched videos at very loud volume levels, thereby affecting the quality of the interview-focused recordings.

3.8.3.3.2 Dyadic interviews

A dyadic interview is a data collection method by joining two participants in an interview (Allan, 1980, Eisikovits and Koren, 2010, Reczek, 2014). I included all interviews involved two family members as dyadic interviews.

There are two reasons dyadic interviews were conducted in this study: firstly, because there were only two family members available, even though the actual number of the family members was more than two. For example, when I visited Agung's home to conduct a family interview, only Pak Agung and Bu Sari were available, even though the family and I had agreed to do the interview on that day. Pak Dony's family is another example of a dyadic situation. The actual number of

the family members is four; however, only Pak Dony and one of his daughters were available during the study, because the other family members lived in another city.

The second reason I conducted dyadic interviews was because the family members chose to do the interview with their spouse. I conducted dyadic interviews with Hendra's family: a) the first was with pak Hendra and his wife, b) the second was with Wina and Gama, Pak Hendra's daughter and son in law. Conducting dyadic interviews enables the researcher to observe interaction between the two family members. Also, a better understanding can be captured from two accounts than one (Allan 1980). Once again I chose Pak Hendra's family. Pak Hendra mentioned during the interview that he preferred to manage his stress using a spiritual approach, and it seemed other family members did not notice this. During the interview with his daughter and son in law, they discussed that their father may need to manage his stress properly by taking more breaks from his activities. Pak Hendra engaged in many activities, such as writing books, as well as participating in social and religious activities. His children were unaware that their father had worked out his own way to manage his stress.

3.8.3.3.3 Individual interviews

This method involves a face-to-face interview between the interviewer and a family member. This approach enables the interviewer to obtain sensitive information that is unlikely to be revealed in front of other family members (Morgan et al., 2013). As an example, during her confidential individual interview, one of the daughters in a family revealed that the family has an issue that was always troubling her father. Also, the individual interview gives a chance to capture information, from an individual's point of view, about the same events that other family members experienced without any influence or bias from them (Reczek, 2014). Another

example of an individual interview's value was when, during their separate interviews, two brothers revealed they had different opinions about the situation in their house. Individual interviews ranged from 11 minutes to 1 hour. Some family members could not, or perhaps would not, give much information, while others were very talkative and helpful.

Individual interviews were conducted for several reasons. The first cause was if the family members were unable to attend the dyad or family interview. One of Pak Wimar's daughters was unable to join the family interview because she was working that evening. Therefore, I arranged an individual interview for her, which was successful. The second reason an individual interview was employed, was when family members refused to be interviewed with other family members. For example, Pak Agung's son did not want to join the family interview, even though he was available at that time. He asked to be interviewed after the others, which is what happened. The third reason the individual approach was employed was when I thought I needed more information from other family members who lived separately from their parents. Pak Sadu only lived with his wife, Bu Marni, and so at first I only interviewed this couple. But, once I had engaged with them I found out that they had interaction with two of their daughters every day. Either they visited their daughters or the daughters visited their parents. Therefore I decided to interview their daughters individually, which I managed to do.

3.9 Data analysis

This section covers the data analysis process of this study, which includes: 1) discussion about the data management, 2) the analysis process and theories and 3) concepts that were used as the lenses through which to interpret the data.

3.9.1 Data management

Data management is simply an organisational process that enables the researcher: 1) to quickly distinguish distinct items, types and versions of data, 2) protect the participants' confidentiality, and 3) also provide an ongoing record of the analysis process, which will include decisions made during the process (Guest, 2013).

For this study, observation and informal conversation were converted into field notes; the tape recorded interviews were transcribed by the researcher. In addition to fieldnotes and transcription I also recorded my personal comments, judgements, moods, attitudes and reflections in my research diary, which was a separate document from the field notes and transcriptions. All participants were given pseudonyms to ensure their anonymity, and all identifying information related to the participants was removed to protect participants' privacy and data confidentiality. I then input all the data into the qualitative research data analysis package: NVivo 11. Folders were created for data, based on the source of the data that was either field notes or interview transcripts; I also created a folder for my research memos.

3.9.2 Analysis process

Data analysis in qualitative research has been defined as a systematic process to search, arrange, understand and present all of the interview results, field notes and other materials that have been generated during the data collection stage (Bogdan, 1982). Data analysis in qualitative studies does not follow a linear paradigm, which means there is no particular time to start analysing the data (Huberman, 2002). However, analysis can even be started before the data collection process. Hammersley and Atkinson (2007) suggested the analysis process begins in the pre-fieldwork phase, initially to formulate the research problems, and then

continues during the writing process. According to O'Reilly (2012) data analysis which links the data collection process, analysis and writing up inextricably, is an iterative-inductive approach, and this approach is informed by inductivism. Similarly, my analysis adopted iterative-inductive approach, began before I started data collection through levels of my reflexivity; the process formally started by analysing the first field notes. The analysis then continued alongside the data collection, and this strategy helped me to collect better data (Miles, 2014). Coffey and Atkinson proposed some approaches to the generating of ideas as the outcome of qualitative studies. The first step of an analysis strategy is the coding process. Coding is essential as a means of relating the data to ideas (Coffey and Atkinson, 1996).

The coding process aims to organise data into more meaningful categories. I started with the data from observations, reviewing the field notes, and then the data gained from interviews. For the interviews data I started with listening to the recordings once and transcribing them verbatim, using transcription software. During the transcribing process, transcription symbols adopted from Silverman (2013) and (Jefferson, 2004) (see Appendix 3) were used to indicate: i) unclear sections, ii) laughter, iii) responses requiring comments and iv) overlapping speech. The field notes were typed in a Word document. I then contrasted and compared the data from and within participants and sources: the observations and interviews. The process of coding itself would start by creating general categories; for example to correspond with the questions in the interview. Another technique I used to code the data was by asking questions: "what happened in here?", "what happened to this family?" I also contrasted one family member with another; and one family with another. The codes were then categorised accordingly. During the coding process, I kept the interview notes and field notes in Indonesian, but the code labels were in both Indonesian and English. An example of the coding is in Table 4 (page 134): Ari

Sawitri (AS) asked questions to participants related to interventions they have made to control their hypertension.

Table 4: Examples of emergent patterns from codes

Transcript raw data	Codes	Theme
<i>Most of the time, when his pocket is full I say 'Pak, can you reduce the nasi be guling?' (a Balinese dish consists of rice and roasted pork, mixed pork and vegetable salad, fried innards of the pig, soup with pig fat) only for him to reply 'Well, when will I have the time to enjoy it, now is the only time I can enjoy it'. He would say that. (Rina)</i>	Compromising meals due to extra money	Economic
<i>Pak Dony admitted that he could not provide himself a proper diet to control hypertension, because his family rarely cooked; they mostly bought meals from the food stalls to save money and time. (Fieldnotes)</i> <i>Ee in average (my blood pressure) over 140 (mmHg), the cause I don't know. As in a book I read it is tolerated to 140 (mmHg), it is because the age factor, food as well, because I don't cook my own foods, sometimes for the purpose of obtaining better taste, the sellers add food enhancer and sort of thing, so the customers stick with them. For food I never thought about it, I never cooked it by myself, very rare. (Pak Dony)</i>	Compromising meals due to lack of money	
<i>Pattern..lifestyle..the sleep pattern! The rest. (Mila)</i> <i>His lack of sleep, it's because of soya milk (Bu Karti)</i> <i>Lack of sleep is the cause. (Mila)</i> <i>Soya milk made him unable to sleep. (Bu Karti)</i> <i>Blood pressure increases. (Mila)</i>	Earning money disturbed sleep patterns	

Once coding and categorising was completed, I retrieved the data using the query feature that is available on NVivo 11. I then started to explore the codes, and searched for patterns, irregularities and differences in order to progress into interpretation.

Interpretation is a further process, after the data are managed and organised. As Coffey and Atkinson (1996, p.139) suggest, analysing qualitative data does not stop at coding and retrieving data fragments, but the process is continued 'going beyond' the data to develop ideas. The interpretation process was then formally labelled as *generalising and theorising* (Coffey and Atkinson, 1996, p.153). In this process I generated ideas through imaginative and intellectual efforts, and embraced relevant theories to generate theoretical ideas relating to the outcome of this study. The analysis was drawn based on general system theory, agency concepts, and protection motivation theory. The analysis process in ethnography is iterative, which requires the investigator to move back and forth between ideas and data (Hammersley, 2007). Similarly, I also kept contrasting and comparing one family to another, to discover patterns, and then link my ideas with related theories. Theories to which I related my data are discussed in page 137.

The process of generalising and theorising includes making decisions regarding how the study will be presented. According to Coffey and Atkinson (1996, p.108) analysing information gained from qualitative research is not merely a matter of classifying, categorising, coding, or collating data; the analysis should also include the 'representation or reconstruction of social phenomena'. In ethnographic research, textual representation of the relationship between data and theories considers the emic and etic categories (Hammersley, 2007). Hammersley (2007) suggests the emic category is the way themes are organised by applying indigenous cultural categories; meanwhile, the etic categories reflect the analyst's ideas. In focused ethnography, included in the process of generalising and theorising is the challenge to find the linkage between emic and etic perspectives (Roper, 2000). For this study I took the etic perspective into account to present the research, because it enabled me to develop broader ideas across families, which differ contextually (Olive, 2014)

During analysis process I made notes when promising ideas arose. These analytical memos were very helpful throughout the analysis process. Other than promising ideas, the memos reflected my personal feelings during the fieldwork. Atkinson (1992) suggests feeling anxiety can limit the data collection process and leads to tunnel vision restrictions. In addition, the memos also recorded the development of ideas as I noted my growing understanding of the data, the relationship of the data with wider theoretical perspectives, and the changing of ideas over time (Roper, 2000). Please refer to Appendix 15 for an example of analytic memos.

The analysis results are presented in a feedback loop diagram in the 'Findings' chapter. The diagram is a conceptual framework designed to summarise the family's experiences in hypertension control. The feedback loop diagram represents the dynamic interrelationships of a complex system (Kim, 1993). To communicate the dynamics of a system the diagram utilises a set of symbols: variables, causal links with polarity and symbols to identify feedback loops with their polarity (Schaffernicht, 2010).

The complexities of healthcare can be overwhelming, yet in order to simplify workflow models we may be missing the real-world experiences of clinicians and the true complexity of care.

Simplify the complexity of a system into a workflow model potentially remove the real-world experiences (Browne, 2017). For example, if a patient took medication regularly the practice should maintain the blood pressure within a normal range. However, the other family members described how family problems had been burdening the patients, therefore the blood pressure sometime increased when the family experienced internal problems. The diagram illustrating quantitative approaches tend to focus on small numbers of linear relationships. Meanwhile there are various interactions and relationships between variables, and involving dynamic

process along those process (Browne, 2017). For this study the feedback loop diagram elicits the themes, theme-related aspects and relationships that describe the behaviour of a family as a system in hypertension control. The feedback loop diagram was constructed by bringing together the themes and concepts of general system theory, agency, and protection motivation theory (Laurenti et al., 2016). For this study the feedback loops represent aspects in the 'family as a system', whether as the balancing or reinforcing influences in hypertension control. Please refer to page 211 for further explanation of feedback loop diagram used for this study.

3.9.3 Theories and concepts used in interpreting data

In chronic disease management, the health behaviour theorists encourage the patients to be able to control themselves in order to achieve better health. As an example, the Theory of Planned Behaviour (TPB) assumes that individuals have control over their intention to change their health behaviour. This principle of the theory is called *perceived behaviour control* (PBC), with the control being perceived by the individual as internal (self-efficacy) but influenced by external factors (perceived controllability) (Ajzen, 1991). PBC has shown variability in measuring the level or degree of an individual's intention to perform a specific behaviour; self-efficacy accounts for more variance in intention, whereas controllability has been shown to be less reliable (Ajzen, 1991, Armitage and Conner, 2001). TPB is a self-report measurement; therefore it can be argued individuals lack knowledge of the kind of external factors that may facilitate or mediate the person's intentions. In other words, the hypertensive patient in the family may be unaware that those factors even exist. Seminal work with the locus of control concept has placed the individual as the central controller in their lives (Rotter, 1966, DeCharms, 1968, Adler, 1955, White, 1959). It has been argued that each individual's levels of motivation, affective states and actions are influenced by what they believe (Bandura, 1995).

Control itself is the ability to use power in order to influence or direct people's behaviour or the course of an event (McIntosh, 1963). In line with self control in disease management, individuals exert their willpower to be able to make changes over the course of the condition's management. The position of the individual to be able to change a situation through power exertion is called 'agency'. Giddens (1986) describes the agency-power relationship as the ability of an individual to make a difference or to change a course of events. When someone is able to make a difference or change a condition, it means that individual exercises power. Daniel Kipo (2014), in line with Giddens (1986), argues power is not a contest of domination between groups or classes; instead power has a close relationship to agency. Giddens (1986) suggests any individual in a social relationship has a certain amount of power over the other, because power is always two-way; power is a relationship between autonomy and dependence. For both agency and structure, power has transformative capacity, as changes result from the interaction(s) between agency and structure (Giddens, 1986). Lukes (2005,p.70)) suggests human powers are:

"Abilities activated by agents choosing to do so (though the choice may be highly constrained, and alternative paths unlikely to be taken) and also passive powers which the agents may possess, irrespective of their wills."

However, in a family setting, control over disease does not solely belong to the individual with that disease. This current study involves individuals who are a part of the Indonesian family system; a situation making it extremely difficult, probably impossible, for an individual to have total control over the management of their condition and its treatment. Instead, various sources of power exerted their influence during the process of blood pressure control in daily life. Therefore general system theory, agency and structure concepts, together with protection motivation theory, are discussed in the following section to provide an overview of those theories and concepts that were used to interpret this study's data.

3.9.3.1 General system theory (GST)

This study explores the family experiences in hypertension management in the specific context of Indonesian daily life. 'Family' consists of multiple individuals with various perspectives, which results in the individuals experiencing differing family realities. The family influences individual members, with those individuals later contributing to their family's dynamics (Reczek, 2014, Aarons Gregory et al., 2007, Burton Linda and Hardaway Cecily, 2012, Ryan et al., 2012, Carr and Springer Kristen, 2010). Thus, from being extensively studied the family has been recognised as a predominant influence on a member's illness, its treatment and its general management (Denham, 2003, Jonsdottir, 2013, Knafl et al., 2013, Leahey and Wright, 1987a, Leeman et al., 2016, Mendes et al., 2017). The interactions of the members within a family have resulted in chain reactions affecting and involving members both directly or indirectly (Wright and Leahey, 2013, Christie-Seely, 1985). The action and reaction cycle is evidence of the relationship and communication among the family members; a cycle which is known as a central feature of a system (Bavelas and Segal, 1982, Bateson et al., 1956). The system approach has also been widely used in family research (Christie-Seely, 1985, Connors and Caple, 2005, Cox and Paley, 2003, Fingerman and Bermann, 2000, Heiden Rootes et al., 2010, Ng and Smith, 2006). This study follows the nursing research paradigm of the 'Individual/Family System' (Robinson (1995) because this includes the interactions and reciprocity that exist between the individual and their family; both the individual and family are units of interest and consideration. Robinson (1995) also divided the data to be collected in the family nursing research into three levels: i) individual, ii) relational and iii) transactional. For this current study, all three levels of data were utilised. The first *individual level* involved data from individual interviews with a single family member. The second *relational level* involved individual-level data collected from two or more family members; information that was obtained through

dyadic interviews and interviews with other family members. In the third *transactional level* data was obtained from family members during their interaction with each other as a reflection of their relationships; through group and dyadic interviews and observations. The groundwork in the family nursing field was mainly based on the general system theory suggested by Von Bertalanffy, an Austrian biologist (Friedman et al., 2003). This current study uses general system theory to underpin and inform my research. Feetham (2018, 1984, 1991) suggested if the unit of interest in family research is the family, and the level of data is individual/family system, then family system theory should be chosen as the theoretical framework for that research. A critique of general system theory, as the underpinning theory of this study, is presented in the following section.

3.9.3.1.1 Overview of general system theory

It has been suggested that general system theory (GST) is the most influential framework to facilitate an understanding of 'family' (Bomar, 2004, Friedman et al., 2003, Kaakinen, 2010). The original GST was offered by Von Bertalanffy in 1950, and was derived from physics and biology as an exploration of "wholes" and "wholeness"; however, the author then suggested that the principles could be applied to 'general systems', including those that were sociological in nature (von Bertalanffy et al., 2015). The system in general is defined as "sets of elements standing in interrelation"; with the term 'interrelation' meaning one element behaving differently in each relation within the system ((von Bertalanffy et al., 2015, p.38). However, von Bertalanffy et al., (2015) argued the focus of science in the past primarily investigated the complexity of phenomena by confining the observations solely to elementary units independent of each other. Such an approach failed to discern if various behaviours of the parts were the results of dynamic interactions between those parts. Thus he focused the GST's aim at the meaningful integration

of science and scientific analysis, whilst also suggesting social sciences, such as sociology, which studied human groups or systems such as 'the family', should the approach of GST.

From the system viewpoint, the family is assumed to be a system that is greater than, and different from, the sum of its parts; a system that is characterised by its wholeness, feedback loop, equifinality, and the presence of boundaries and hierarchies (Bomar, 2004). Cybernetics, a principle of feedback providing the mechanism and information for goal-seeking and self-controlling behaviour (Von Bertalanffy, 1973, p.90), is the fundamental concept to explain self-regulation that is happening in an open system. The cybernetic model explains the exchanging and transferring of information as it occurs in an open system. This study uses cybernetics to explain the family's interrelationships.

In order to gain a deeper understanding of the family as a system, the following sections of this chapter elaborate the aforementioned concepts: 1) closed and open systems, 2) wholeness, 3) feedback loop, 4) equifinality, 5) boundaries, 6) hierarchies, and 7) cybernetics.

3.9.3.1.2 The closed and open system

The first characteristic of the system by von Bertalanffy (1973) is that it involves closed and open variants. The closed system is considered to be isolated from the environment, being mainly identified in the process of, and associated with, physics. An example of a closed system is one using thermodynamics. Von Bertalanffy et al., (2015, p.126) says 'in a closed system environment, the equilibria are based on reversible reactions'. Meanwhile, he considered living organisms to be open systems, as they are characterised by their ability to maintain their composition by exchanging matter with the environment, despite being involved in continuous irreversible processes. This process can be seen to involve importing and exporting,

the building-up and breaking-down of the living organism's components. A family is a living organism unit and an open system, characterised by the idea that no one family can live in isolation. Thus, exchange from the environment to the family members, and *vice versa*, matters in order to achieve a steady or balanced state (von Bertalanffy et al., 2015, Stanton, 2010, Datchi-Phillips, 2011, Bavelas and Segal, 1982). The environment that the families exchange matter with includes: 1) socioeconomic status, 2) work, 3) cultural differences, 4) politics, 5) healthcare, 6) the physical environment, 7) safety, 8) community, 9) religion, and 10) media (Stanton, 2010).

3.9.3.1.3 Wholeness

A system concept involves a 'wholeness' or whole entity. An expression that is usually quoted to describe a system is 'the whole is greater than the sum of its parts'. This expression was called 'mystical' and 'trivial' by von Bertalanffy (1973, p.55) because it just describes the constitutive characteristics of a system; where systems are not explainable from the characteristics of their isolated parts. In other words, such an explanation neglects the interrelationship of a system's constituent elements. A system cannot be explained just by observing one part of it, because all its elements are interrelated and the behaviour of one element to each other element will differ. When this complex interrelationship is observed as a whole it will show new conditions/ situations that are entirely different and even greater than the sum of its parts.

Therefore to have an understanding of the interrelations of a system's elements one needs to understand the whole system. In a family as a system, the example of it as a functioning whole is observed when we want to understand the development of an individual's behaviour. That behaviour will be greatly influenced by the interdependency of family members during their daily interactions (Minuchin,

1985; Hammer, 1998). Individuals' behaviour patterns are developed since they are young as the result of interaction with multiple levels of family relations. The patterns start with their parents at a nuclear family level, and the grandparents at an extended family level. Furthermore, when the children grow up the behavioural patterns are the result of interactions with their work colleagues, the service providers who may be responsible for the process of family functioning, and the environmental dynamics: global, regional and local (Cross and Barnes, 2014, Hammer, 1998, Carter and McGoldrick, 1989). Thus, to understand the behavioural elements of an individual in a family, all of the parts that influence that individual's development should be scrutinised.

The dynamic interaction of its elements is the basis of the open system model, and the goal of the interactions is to reach a steady state. The elements in an open system communicate through the feedback mechanism, so the desired value is maintained and the target is reached (von Bertalanffy et al., 2015). General system theory borrows the concept of cybernetics to explain the self-regulating features in an open system. The following section discusses the self-regulating features of the system, which include: 1) cybernetic theory, 2) feedback-loops and 3) equifinality.

3.9.3.1.4 Cybernetic theory, feedback, and equifinality

Cybernetic theory is a theory to explain a control system, suggested by Norbert Wiener in 1948. Wiener's cybernetic theory is one of the underlying concepts used to explain the self-regulating feature in GST (von Bertalanffy et al., 2015). The basis of cybernetics is the circular process of feedback, involving the transmitting and returning of information within a system from and to its parts (Wiener, 2013). The feedback in a system is the control which is also known as 'the thinking operation' or 'considered know-how' in the process of maintaining the

steady state (Rose, 1974, p.101). Rose (1974) added that the cybernetic concept covers the way of communication, control of and correcting behaviour in the event of changed conditions, so the system can adapt itself to the environment in order to attain the desired steady state. Von Bertalanffy (1973, p.132) suggests a remarkable characteristic in the steady state is that of equifinality. This neologistic concept refers to a condition when the final state changes because of the alteration of initial conditions.

In the family as a system, the circular cybernetic-type feedback is captured in a repetitive pattern of interactions. Those repetitive interactions occur as a human system is developed through a 'trial and error' process, which is then captured in a family system as that system constantly adapts to its ecological context (Bateson, 2000, Dallos, 2005). Feedback is the control component in a system, and this feature in human systems is demonstrated through behaviour known as 'reflexivity': *a capacity to monitor one's actions* (Dallos, 2005). The author added that in a family system, the feedback is encapsulated in the idea of assessing and identifying the needs of a particular situation or relationship. Adjustments are made to input-deviations in order to maintain stability. This feedback process can be clearly observed through various social relationships, rituals and family life (Bateson, 2005).

The cybernetic epistemology examines the interactions in relationships between individuals as both circular and reciprocal; consequently each part of system is viewed as equal or designated as making a similar level of contribution in maintaining the interaction (Mackinnon and Miller, 1987). The interaction between the parts of a system, according to cybernetics, is still unclear. In particular it is still not known how exactly the process in each part of a given system communicates, so they can react towards or with each other. Thus, this study proposes the interactions in the family setting by focusing on hypertension control to understand the feedback mechanism in play.

3.9.3.1.5 Boundaries and hierarchies

Boundaries in an open system are needed in order to recognise what belongs to the system, since there are also influences from without the system incoming from the environment. Thus boundaries could maintain a system's identity (Cilliers, 2001). Meanwhile, hierarchies refer to components dominating the behaviour of the system, due to mechanisation; a process that leads to the establishment of leading parts (Bertalanffy, 1973).

As an open system, the family cannot be isolated from its environment, and the boundaries are considered as interpersonal rules that differentiate the family from its outside world (Langman, 1984). The boundaries in the family system enclose both physical and symbolic barriers (Broderick, 1993). The physical barriers include physical efforts to mark territories such as doors, fences, and windows. Meanwhile, there exist symbolic barriers of spatial territory; an example being that individuals in a family are expected to knock when entering another family member's space (Broderick, 1993). Each family member also has boundaries, and this creates interactional sequences that then form the hierarchical structure of the family; and finally dictate the family's rules (Minuchin, 1974). Minuchin (1974) describes a family as an organisational structure consisting of subsystems such as the parents, spouse, and siblings. This hierarchy in a family dictates how the family members interact, as each subsystem has its roles, responsibilities, and functions. Weber (2009) suggested that all societies are stratified; meaning in each society some members are more powerful, have more control over property and gain greater prestige than other members.

Corresponding to Weber's concept of stratification within a family, individuals with more power or resources will be the ones who are in charge and, as a

consequence, carry out decisions in and for the family (Broderick, 1993). However, power is not solely exerted by just one individual in a family, because each subsystem has different levels of power. Thus this model creates a hierarchy of power within the family system (Minuchin, 1974); for example children are perceived as inferior to the adults, and particularly their parents (Faber, 2002, Shaw et al., 2004, Nock, 1988). Thus parents have the power, at least in theory, to control their children (Nock, 1988). Gender also creates power stratification, such as a husband having more power than his wife (Nock, 1988).

Even though the GST has a strong influence in family intervention and therapy, there are critiques of this concept which are elaborated in the following section.

3.9.3.1.6 Critique of general system theory in family research

The GST has been widely used to explain the complexity of the family and families (Friedman et al., 2003, Bomar, 2004, Cox and Paley, 2003). However, scholars have criticised the GST because it fails to describe the individual's responsibilities in a family (Spronck and Compennolle, 1997, Merkel and Searight, 1992, Cottone and Greenwell, 1992). The main difficulty identified is that the 'holism' concept in GST sees an individual as less important than the larger system, especially the family. Individuals are equally important, as they are the component parts of their family. By equal means, each individual in a family has the ability to influence every other member. For example, in health care, the healthcare providers would find problems at the individual level, and they would give interventions to the patients, but they could not isolate those individual patients from their family. Bomar (2004.p.105) emphasises:

"Individuals do not make health decisions autonomously and in isolation. Health is the family event."

The process of adopting healthy or health-centric behaviour by an individual is strongly influenced by her/his family, due to the individual's and his/her family's interrelated character. Therefore, system theory is used to understand individuals in their natural settings, which in this study is the family. This approach is used in order to discover the underlying reasons for the individual's problems (Hammer, 1998, Friel et al., 2017, Liu et al., 2014, Ransom, 1982, Ransom, 1983). Parse (1990) made the observation that health 'is a personal commitment'; but actually health is co-created through the human-environment interrelationship. The closest environment for individuals is their family, so it is arguable that health is not a static condition; it exists in rhythmical patterns instead. Knowing details of humans' interconnectedness with their worlds would reduce the environmental barriers and assist health care providers in tailoring interventions that enhance individuals' responsibilities over their health. Nevertheless, the GST fails to explain how the process of interactions between the micro elements (individuals) finally affects the macro level (the family). This omission is the flaw in GST as it dismisses, or at least ignores, the power in family interactions. The system theory denies / ignores the concept of interpersonal power due to the theory explaining power as a circular domain, while in reality power is described and experienced in a linear domain (Merkel and Searight, 1992). Other than that, the ability of the parts to exert power on one another is considered as an epistemological error that perpetuates the 'myth of power' (Mackinnon and Miller, 1987). The 'circularity of power' notion implies that all elements of a system are: 1) equally involved in maintaining the interaction among each other, 2) have equal influence over the outcome, and 3) are equally free to participate or not (Mackinnon and Miller, 1987).

The aforementioned equality understanding is slightly different to what is explained by Beckman-Brindley and Tavormina (1978), who suggested that with equality in a family, it is not necessary that the actual return of each be equal. They

argued that the ratio of rewards to investments must be equal, or at least perceived as such. However, Beckman-Brindley and Tavormina (1978) also suggested that the exchanges in a family always involve power and dependence, even though the exchanges could be equal or unequal, stable or unstable. Those same researchers suggested that stability does not result from the equality of the exchange; rather stability relates to the individuals' perceptions of the resources, the values of those resources, and the equity of the exchange. By making this statement they unavoidably confirmed that power significantly contributes to family interactions. Thus, in attempts to gain understanding of micro (individuals) and macro (the family) interactions, the family system and cybernetic theory should give a chance to agency and structure concepts to act as explanatory channels; an idea which is discussed in the following section.

3.9.3.2 Agency and structure

The adoption of healthy behaviour, such as healthy diets, regular physical exercise and quitting smoking, is largely a matter of individual choice or is principally shaped by structural variables (Cockerham, 2005, Veenstra and Burnett, 2014, Weaver et al., 2014, Abel and Frohlich, 2012, Putland et al., 2011, Mulvaney-Day et al., 2012, West et al., 2015, Dowding, 2008, Choby and Clark, 2014). Choby and Clark (2014) claimed the positions of individuals within the structures or agency, with the characteristics of freedom and domination, contribute to producing the structures. The person within the structure experiences freedom and domination as either oppressive or invisible and beyond awareness. Meanwhile the structure is defined as "the relationship between variables" and is depicted as red bricks (individuals) that are put together; as a result we get different buildings (social structures) (Dowding, 2008, p.24).

Dowding (2008) added that individuals might be formed into different social structures, which will then form different systems of power. Choby and Clark (2014) suggested that within

the structure of a society, its institutions and power relations are produced and reproduced. In a healthy lifestyle, structure and agency call for a recursive and co-dependent dynamic. Actions by the agency (individuals) are impossible without structure, because the action conducted by the agency begins with a given structure that was itself the result of prior actions (Veenstra and Burnett, 2014). Hays (1994) suggests structure may be seen in three ways: i) structure as a creation of human beings, ii) structure as enabling and constraining, and iii) structure at different levels, so more or less hidden from everyday consciousness. In relation to structure as enabling and constraining, the following paragraphs discuss the issues of freedom and domination; concepts that bind the agency and structure to give the structure its characteristics.

3.9.3.2.1 Freedom and domination

Choby and Clark (2014, p.98) claim that freedom and domination dynamically bind the interrelation between the agency and the structure. Freedom is defined as *“the ability of any individual to direct or play a role in creating structure”*. When individuals are able to participate in the creation of material and the symbolic structures that frame their collective lives, then they have ‘freedom’. Freedom is related to the position of an individual within a given structure, which is likely to affect the other agency or individuals within that structure (Einspahr, 2010). Einspahr (2010) suggested domination is a form of power exerted by individuals or groups to interfere with others’ rights. Power is developed through a contingent social process, and is embedded in individuals at the level of everyday practice; a process that is made to appear ‘natural’.

Hays (1994), says ‘family’ can be enabling as well as constraining, due to the exertion of freedom and domination of individuals within the family. Freedom and domination are the realities of social life, which can be understood as an interplay of power within the structure (Lukes, 2005, Bates, 2010). Even though there are hierarchies in a family, the power in a family is dynamic and strongly influenced by social exchanges as the consequence of the

interrelationships among the family's members (Beckman-Brindley and Tavormina, 1978). Beckman-Brindley and Tavormina (1978) suggest there is no fixed power held by one party in a family; the power is dynamic. This situation is because the relationships among a family's members always involve *power and dependence*. This fluidity is the consequence of the constant processes of reciprocal exchanges of valued resources, in which each person experiences both power and dependence regarding the others.

3.9.3.2.2 Micro-macro interactions

The integration of agency and structure in systemic settings has been discussed in work by Goldspink and Kay† (2003, 2004, 2007). They suggested the reciprocal relationship between the micro level (agent) and the macro level (social structure) has not been defined clearly in the 'system environment'. Goldspink and Kay (2007) create understanding of non-linearity and its consequences of natural and social phenomena in the frame of complex systems, as well as to build tools to explore such a system with multi-agents. However, they have not obtained any firm and consistent results from the studies they conducted, due to the complexity of the organisations they sampled. Even though Goldspink and Kay (2007) studied the concept of system, an organisational system has different characteristics to those of a family. Lutz (2006) has described the differences between a family system and an example of an organisational system.

1) The first difference is in terms of membership: the members in a family are automatic and forever. In an organisation the members are needed because they have certain skills that are useful for the organisation, and those members may not remain involved if they are not needed anymore.

2) The second difference is the authority: in an organisation it belongs to the top leader, such as the CEO; meanwhile in a family there is normally no urgency for someone to be the explicit leader.

3) The third difference is in the process of decision making: in a family, the decision making process usually depends on the circumstances, but in an organisation that process is clearly defined.

4) Lastly, there is a difference in priorities. The priority in an organisation is an obligation for every member to achieve; meanwhile in a family, each member has their own priority or priorities.

Therefore, this study attempts to understand the interaction between agency in the family as a system context.

3.9.3.3 The protection motivation theory

Perceived severity of an illness predicts the patient's behavioural change; a procedure which is widely used in individual health behaviour models, with its roots in the Health Belief Model (Rosenstock et al., 1988). The perceived severity of an illness is a concept that utilises fear as an affective state protecting one against danger (Rogers, 1975). One of the prominent theories that utilises fear to persuade the individual to change their behaviour is the protection motivation (PM) theory by Rogers and his colleagues (1975, 1983). The first version of PM theory was offered in 1975 and it was revised in 1983, as the second version. The initial theory by Rogers (1975) emphasised that 'fear appeal communication' would initiate a cognitive appraisal process if the following three concerns are present: i) the severity of the event, ii) the probability of the event actually occurring, and iii) the efficacy of a recommended coping response.

Eight years later Maddux and Rogers (1983) incorporated *self-efficacy expectancy* (Bandura and Adams, 1977) as the fourth component of the PM theory. In this current study PM theory has been widely used to predict health behaviour changes, such as in smoking behaviour, physical exercise, condom usage, medication compliance and diets (Plotnikoff and Trinh, 2010, Norman et al., 2005,

Tulloch et al., 2009, Plotnikoff and Higginbotham, 1998, Ho, 2000, Ali Morowatisharifabad et al., 2018, Park et al., 2011, Flynn et al., 1995). However, those studies mainly examined the individuals' intentions to change their behaviour, which may not fit the Indonesian context where individuals are a) closely associated with and related to their families and b) live in intergenerational family units. On the other hand, there are studies that attempt to expand PM theory's application into different family settings. For example, the extension of PM theory into parents' intentions can be seen in nuclear family settings (Flynn et al., 1995, Westcott et al., 2017, Lwin and Saw, 2007, Norman et al., 2003). However, the validity of such research evidence needs to be qualified as it is solely based on self-reported behaviour, without evidence to demonstrate the complexities of family life. Meanwhile, Soames Job (1988, p.163) argues:

"Self-report based variables are susceptible to experimenter effects and demand characteristics, to such a degree that demand characteristics formed the basis of one important theory of attitude change. Further, it is well recognised that the assumed correspondence between self-reported attitude change and behaviour change is not supported by the data."

Based on the aforementioned critique, this study attempts to expand PM theory in the frame of 'the family as a system', to fit individuals' conditions into an intergenerational family context.

3.9.3.4 Summary

This study is informed by the general system theory (Von Bertalanffy, 1973) because its unit of interest is the family, with the levels of data involving both individual and family systems. However, the GST has not yet clearly shown the power in family interactions, because it assumed power resided in a circular domain; whereas in reality power is described and experienced in a linear domain. The circularity of power explained by the GST consequently implies that all the elements of a system have equal positions in maintaining their interactions. GST also suggests that those elements are equal in their influence upon the outcomes/results,

and are equally free to participate or not. In attempts to gain understanding of the dynamics of micro (individuals) and macro (the family) interactions, both the family system and cybernetic theory should give a chance to agency and structure concepts to facilitate desired explanations. Other than that, this study also makes use of protection motivation theory, in an attempt to expand the practicalities of PM theory in a family intergenerational context.

3.10 Reflexivity

Hammersley (2010, p.568) suggested “*we cannot avoid relying on ‘common-sense’ knowledge nor, often, can we avoid having an effect on the social phenomena we study*”; a point which, if valid, has significant implications for research. Reflexivity is a strategy to remind the researcher to maintain awareness of the participants' backgrounds and experiences, as well as her own, while also staying engaged with the moment (Hammersley, 2010, Patton, 2002, Schwandt, 1997). Hammersley (2010) argues that when a researcher comes from familiar settings, she or he will probably find difficulty in letting go of their long held beliefs, and they find difficulty in holding on to his or her perceptions when confronted with contrary evidence. This situation potentially causes the researcher to lose their ability to view the world from different perspectives; instead she is likely to see the world from only one point of view (Bogdan, 1982).

However, in this study I come from a similar cultural background to all of the participants. Furthermore, I come from a family in which one of the members suffers from hypertension. Therefore, the participants' situations are quite familiar to me; a circumstance which 1) could have influenced the questions I asked participants, 2) my perception of events that I observed and 3) the way I analysed the data. However, I disagree with the academic argument which suggests outsiders are

preferred in qualitative research. In nursing research it is sometimes preferred if the observers have similar concepts to the actors, in order to avoid misinterpretation; especially when observing behaviour (Greenwood, 1984).

Cuthill (2015) suggests it is essential to recognise the positions of the researcher and the research participants, because their positions could raise benefits and challenges for the researcher that could create bias in the study. In my own background, I am a daughter whose mother is affected by hypertension; I have a Balinese cultural background; I reside in Denpasar and I am also a nurse with an adequate knowledge of hypertension. All these factors have placed me in a position where I have only a *narrow 'space between'*: perhaps more 'insider' than 'outsider' (Cuthill, 2015, p. 67). These personal attributes caused me to share experiences with the families I studied; consequently the shared-experience-position allowed me to approach the participants quite easily. For example, some of them agreed to participate in my study because they felt close to me as we lived in the same city. Participants showed a positive welcome towards an 'insider' researcher because they assumed I was an ally they could trust (Gibson and Abrams, 2003). My prior knowledge about the society's context and its culture also benefitted me because I possessed information and awareness that an outsider would not have. As an example, in Bali we celebrate many ceremonies that are based on the Balinese calendar. In addition to the Gregorian calendar, we also use two types of Balinese calendar. The first is based on the moon or *sasih*, and consists of 12 lunar months; the second calendar is based on the rice-growing cycle in Bali, which is the *pawukon*: a *pawukon* year consists of six months. These two calendars are used for religious ceremonies, thus we have temple anniversary and festivals almost every month on the full moon, if following the *sasih* calendar; or every six months if following the *pawukon*. Kacen and Chaitin (2006) emphasised that insider

researchers can usually access information about rites and symbols easier than outsiders, because of their fluency in language and contextual understanding.

As mentioned above regarding prior knowledge of nursing research, my background as a nurse and lecturer leads me to decide what kind of social situation I have to focus on during the observations in order to obtain information that was related to hypertension control. A researcher without a similar background to my own would probably not know what kind of behaviour should be observed to gain optimal information about the study's main focus of interest.

However, in addition to advantages, my background can also contain disadvantages, particularly during the data collection. For example: several times I mentioned about my mother, when I had to make a comparison or to simplify questions to make them understand; however, when I did so and the participants would reply 'oh really? Well, yeah then you know how it is'. The 'you know how', as the participants assume my position as an insider, can be very frustrating; they would not continue their sentences because they assumed I knew what they meant. Berger (2013) suggests the participants would assume the researcher can read their minds, so it is very important for the researcher to stay alert and constantly reflect on their presence, always guarding against the possibility of shaping or influencing the conversation. My strategy to minimise the difficulties when participants were reluctant to answer, because of their "you know" assumption was by asking the same question in the end, which I assumed they have forgotten about my similar background to them, and this actually helped. My background as a nurse and lecturer sometimes appeared to make the participants unsure about their answers. This hesitation mostly happened when they tried to explain about hypertension; they would end their answer with 'Am I right about it? You are a lecturer'. To deal with this situation I would tell them that I was not looking for the *right* or *wrong* answer,

but I trully want to know their opinions and what they thought and actually did about certain things.

3.11 Ethical considerations

Contact with human subjects in the field is inevitable in qualitative research, and consequently this relationship might increase the risk of ethical problems (Silverman, 2013). Therefore, employing appropriate ethical principles during the process of research is very important to prevent harm to human subjects (Bryman, 2004). Standards of ethical research applied in this study include: 1) informed consent, 2) ensuring confidentiality of information and especially participant anonymity, 3) voluntary participation, 4) avoiding harming the participants in any way, and 5) avoiding conflict of interests during the process (Silverman, 2013).

Informed consent is an essential aspect in conducting research because it promotes trust between subjects and researchers; it is an assurance that the researcher will treat them with respect and protect them from harm (Resnik, 2018). It is important to fully inform the subjects about the study: 1) its purpose, 2) methods, 3) intended possible uses of the research, 4) explanations about their participation in the research, and 5) if there are any risks that might arise during their participation (Silverman, 2013). For this study I provided information sheets that provided: 1) information about the study title and research purposes, 2) the data collection methods, 3) advantages and disadvantages of this study for participants, and 4) the activities I will conduct during my interaction with the subjects. In addition, Comstock (2013) argues a researcher has to respect the subject as a free agent; thus it is essential they have the freedom to choose whether to participate or not. For that I also covered the information that the subjects' participation is voluntarily, and this information included participants being able to withdraw from the study at

any time, without giving a reason. They were also able to request the removal of all or part of the information they had provided. Morrow (2013) suggested in addition to adequate information and volunteering, another important element in informed consent is the capability to understand. Therefore, I created three different information forms; for the adult family members, teenager family members and young children. I used simpler language for the younger family members. Please refer to Appendix 4 information sheet for young children, Appendix 5 information sheet for the teenager, and Appendix 6 information sheet for the adult family members. I also included an invitation letter in Appendix 7. All documents were available in the English and Indonesian languages.

Participants deserve their privacy and autonomy, which means the information they provided will not be repeated or shared without their permission (Rose, 2012). To manage and ensure the participants' confidentiality, pseudonyms were used throughout and all references to locations will be changed to ensure anonymity. This aspect of the research is also covered in the information sheet. I also ensured confidentiality by providing individual, dyad and family interview methods; all participants were free to choose whether they became involved in family or individual interviews. If they were uncomfortable sharing information in front of other family members then they could choose to do an individual interview. Furthermore, all transcripts are stored in a password protected computer, the paper or document-based data is and will be stored in a locked filing cabinet, and all devices and filing cabinets will be located in a locked room.

Silverman (2013) argues that a researcher has to maintain all aspects of the participants' well-being, not only physical but also emotional. In this current study participants may disclose experiences which could cause emotional distress to themselves or others. This event was not anticipated, but in case any questions during the interviews caused emotional distress or discomfort for the participants,

the interview will be immediately terminated to give the respondent a chance to decide whether or not they wanted to stop completely, re-schedule, or carry on. Furthermore, any participants who became distressed by participating in this research will be referred, with consent, to their physician. Furthermore, I have experience of working in communities and working with families; therefore, I was aware of the sensitive nature of the research questions and was able to conduct the interviews and observations in an appropriate and non-threatening manner. I also made sure there were no conflicts of interest in this study.

Children and young people are part of families and therefore this study included children and young people (under 18 years old). The reason for including them was because they can contribute to the family-centred debates included in the research (Lewis, 2004). However, since they cannot make such a decision or give consent, it is incumbent on their parents or guardians to make such decisions for them (Resnik, 2018). This principle is in line with Indonesia's Child Protection Law, No 35, 2014, that parents have obligations and responsibilities to safeguard their children's health, development and welfare. Therefore based on those principles, I sought parental consent for the involvement of their children in this study. In addition to parental consent, consent from the children and young people themselves will also be sought.

Ethical approval was sought from the University of Edinburgh's Ethic Committee and the Ethic Committee of the Faculty of Medicine, Udayana University & Sanglah Hospital. In addition, this study also needed approval from the National Unity and Civil Service Protection Agency of Bali Province, and the National Unity and Civil Service Protection Agency of Denpasar. A written consent sheet was provided for each participant, meaning all family members who will take part in this study. All potential participants had the chance to read the information, and based on agreement, I called them to find out whether they agreed or not to participate in

this study. It was pleasing to note that some participants made known their agreement immediately after reading the information I gave. I provided five different consent forms: 1) for the head of the family, 2) for adult family members, 3) for teenager members, 4) for young children, and also 5) for the parents of the young children. Due to my needing access to the family, I then had to get approval from the head of the family. The head of family is the person who is responsible for the people listed in family card (please refer to section: *'the families as study sample'* page 97). I also had to seek for the parents' approval to include the young children in this study. As Morrow (2013) suggests, to include children in a research the parents' consent must be sought. For further information regarding the consent forms used in this study please refer to: 1) Appendix 8 consent form for young children, 2) Appendix 9 consent form for teenagers, 3) Appendix 10 consent form for adult family members, 4) Appendix 11 consent form for the parents, and 5) Appendix 12 consent form for the head of family.

3.12 Methodological rigour

It is important to demonstrate rigour in a research design in order to make a judgment about the quality of the research (Mason, 2002). The established measures of validity, generalisability and reliability, used in quantitative research are irrelevant to measure the quality and standard of qualitative research (Seale and Silverman, 1997, Silverman, 2013, Holloway, 2008, Denzin and Lincoln, 1998). Therefore, Guba (1989) proposes four criteria to ensure trustworthiness in qualitative enquiry. The criteria are: i) credibility, ii) transferability, iii) dependability and iv) confirmability. The following section is an elaboration of those four criteria, as they were applied in this study.

3.12.1 Credibility

Credibility measures: 1) whether the study conducted is truly reflective of the social reality of the participants and 2) whether the research investigated what was originally intended (Maher et al., 2018). Shenton (2004) suggested several strategies to ensure credibility in qualitative research, which were followed in this study to maintain its credibility. This researcher: 1) adopted well established research methods, 2) developed an early familiarity with the culture of participating organisations, 3) conducted triangulation, iv) ensured participants' honesty, v) provided thick descriptions of the phenomena being studied, and vi) recognised my background and experiences as a researcher.

The first strategy to ensure credibility was that the current study adopted focused ethnography, which is an evolution from ethnography, and which is known as one of the oldest qualitative methods (Wall, 2015). Ethnography has been utilised and adapted into various disciplines, to answer questions related to humans in their natural settings (Adams et al., 2015, Speziale and Carpenter, 1995, Wall, 2015). Meanwhile, focused ethnography, as a method evolved from classic ethnography, has been increasingly employed in nursing research (Cruz and Higginbottom, 2013, Higginbottom, 2011, Higginbottom, 2006a, Higginbottom, 2006b, Roper, 2000).

The second strategy to maintain research credibility was by developing early familiarity with the culture of the participating organisations; which in this case were families. Due to the nature of this study, where the primary settings are families' premises, I did not have the freedom to just randomly visit a family without their approval. Thus the strategy I adopted to deal with this situation was to familiarise myself with hypertension control-related activities and situations that the patients might be involved with in their regular time. For example, I attended weekly activities at the clinics, and I also visited the park that I assumed to be the place they usually

went for their exercising. Furthermore, on my first visit to a family, I introduced myself to all the family members, and had conversation with them about general topics; mostly they asked questions about me. Their curiosity about me was understandable, as I was a stranger (albeit a local one) who wanted to visit that most private social group: the family (Gilgun et al., 1992). Therefore I mostly talked about myself to the families, and by doing so I hoped I could enhance trust between me and them, in order to become 'an us'. Shenton (2004) suggests establishing trust between parties is a part of maintaining credibility in qualitative research.

The third strategy is conducting triangulation. According to Denzin (1978) triangulation is the use of multiple methods to prevent personal biases that stem from single methodologies. Denzin (1978) outlined that a researcher can utilise triangulation of methods, data, investigator, and theory. For this study I triangulated the sources of data and methods. For the sources of data, I gathered information from a) individuals and b) families.

The fourth strategy to increase credibility is ensuring the participants' honesty. This strategy was delivered during the recruitment of participants; specifically participation was voluntary, and participants had the freedom to terminate their involvements at any stage. This strategy was adopted to ensure that participants are genuinely wanting to take part in the study and thus are expected to provide data freely and truthfully (Shenton, 2004).

The fifth strategy for research credibility is by providing 'thick description'. This type of description implies a fully detailed account of field experiences, where the researcher makes explicit the patterns of cultural and social relationships being studied, as well as placing them in context (Holloway, 1997).

One of prominent characteristics of ethnographic study is to produce 'thick', as in detailed and thorough, descriptions of the social world lived in and by the subjects (Rock, 2001, Geertz, 1973, p.6). For Guba (1989), the thick data process is also a

strategy to enhance credibility. A thick description provides sufficient details about the phenomenon being investigated and makes explicit relevant patterns of cultural and social relationships, placing them in context (Holloway, 1997). For this study family profiles (see chapter IV) and verbatim quotations are provided to present the actual situations that have been investigated.

The sixth strategy adopted to enhance the credibility of qualitative research is by confirming the researcher has the quality to conduct a qualitative study. The researcher is the central instrument in ethnographic study (Speziale and Carpenter, 1995); thus my background also influenced the perceived credibility of this study. As a researcher, I have acquired previous experience in conducting qualitative studies. Furthermore, I attended qualitative research courses that equipped me with the knowledge to conduct such research. My background experiences and learning helped me to conduct this research.

3.12.2 Transferability

Transferability is a measure of external validity that refers to the probability of the study findings having meaning or relevance in other similar situations (Speziale and Carpenter, 1995). To determine whether a finding is applicable in another context is judged by the potential users of the findings (Guba, 1989, Sandelowski, 1986). Meanwhile, to enable the potential user to assess whether the findings are transferable or not, the researcher will need to provide 'thick descriptions' of the participants and the research process (Korstjens and Moser, 2018). In this study I have included information related to the participants, the study settings, and the methods I used for the investigation. The methodology is elaborated in this current chapter (chapter 3), the study setting in chapter 2, and the participants in chapter 4.

3.12.3 Dependability and confirmability

Dependability is the aspect of rigour in qualitative research that refers to consistency, if and when a study is repeated in the same context (Shenton, 2004, Guba, 1989). Meanwhile, confirmability concerns neutrality, which ensures any interpretations and conclusions are grounded in the data gathered, and not based on the researcher's own preferences (Korstjens and Moser, 2018). Korstjens and Moser (2018) proposed the idea of 'audit trails' as a strategy to ensure dependability. For this study I presented the audit trail by providing: a) the details of the participants' recruitment, b) how the interviews and observations were carried out, c) details of the guidelines for interviews and observation, d) information about the data management and e) how the data analysis was conducted.

3.13 Translation considerations

All interviews were conducted in Indonesian and Balinese languages. The Indonesian language, called *Bahasa Indonesia*, is the state language which I used to communicate with non-Balinese participants. The Balinese language, *bahasa Bali*, was used when I communicated with Balinese participants. The original data would not make sense to English speakers, thus translation is required during the research process to overcome the cultural contextual gap (Santos et al., 2014). When the research is translated (in this study I translated from Indonesian or Balinese to English) then the researcher should ensure that she/he reproduces as accurately as possible the source of text, and is able to express all aspects of the meaning in a manner that is understandable (Larson, 1991). To produce accurate results, Brislin (1970, 1980) proposes the ideal translation process in research involves: i) freeing items from colloquialisms and idiomatic phrases, ii) translating from the source to target language, iii) back translation, iv) making changes if there are any inconsistencies, and also v) ensuring a supply of competent bilingual

translators to examine the original items, the results of translations and back translation versions. All those processes take a lot of time and also require a lot of financial resources; demands which were beyond my capabilities as a student researcher; albeit a mature one. Thus, with careful consideration, and taking advantage of being trilingual, I decided to do the translating myself.

The timing of translation is also a significant aspect in research, because introducing any new steps into the research process may create new methodological issues (Santos et al., 2014). Santos et al. (2014) recommended that translation is conducted in the early phase of a study, so the process of data analysis is more interactive. However, due to time constraints at the early phase I only translated three interview transcripts to provide examples of the data for my supervisors. Meanwhile, the whole analysis process was conducted by keeping the data in its original language, and then the results were translated into English. Twinn (1997) suggests that analysing a translated transcription - in this case from Balinese to English - increases inaccuracy during the interpretation, because some words, idioms, phrases and grammatical structures from an original language cannot be easily translated into English, if at all. Twinn (1997) adds, analysis using transcripts both in original language and English resulted in similar themes. So, analysing data in its original language and then translating the results into English was the procedure chosen to reduce linguistic inaccuracies during the interpretation.

3.14 Research limitations

I will present the key limitations identified from my reflections on this study. First of all due to limitation in resource funding and time, this study only recruited participants in/from urban areas; thus failing to achieve a broad participant spectrum from the rural, as well as urban, families of Indonesia (Mulyana, 2014). This limitation may cause the findings of this research to only be applicable to patients in

urban areas, particularly as there are significant differences between rural and urban areas and populations in Indonesia. Those who live in urban areas benefit from access to advanced healthcare services, and public amenities, that cannot be obtained in rural areas. The way of life in rural and urban areas is also different; thus gaining an understanding about both areas may support the improvement of the health status of the populations in both locations. Therefore, further research that includes participants from rural areas is needed in order to compare rural data with the findings from urban areas.

Secondly this study is limited by the fact I collected and analysed the data by myself; a procedure which represents a potential source of bias. This limitation emerges because a researcher can be too subjective (Bryman, 2004). In order to minimise this limitation, I incorporated two different data collection methods: specifically interviews and observations. The interview data can be verified during the observations and *vice versa*. In addition, I conducted three different types of interviews that I used to verify the data.

The third limitation of this study relates to gaining access to conduct observations in the families' premises. The time available for me to conduct observations was very limited. Some families set the duration for my visit to their premises. Meanwhile, the more relaxed families spent a great deal of their time attending religious ceremonies. This limitation at times caused a less than complete picture of the family to be formed. My strategy to minimise the limitation and to construct a more complete picture of the family was by maximising my time during the interview, asking a majority of questions that related to the family's life and habits. In addition I also agreed to join the families when they hosted family gatherings, and offered to help during the gatherings; all of which provide me with valuable family insights

Finally, a qualitative study attracts criticism for the lack of the generalisability of its findings; especially if it is viewed through quantitative spectacles (Bryman, 2004). However, to apply statistical-probabilistic generalisability, the goal in quantitative studies, to a piece of qualitative research is problematic because of the differences in term of ontological and epistemological assumptions. Fundamentally, the ability to generalise findings is not the goal when conducting qualitative research (Smith, 2018). Guba and Lincoln (1985) argued that there is an opportunity to generalise qualitative research findings without having to rely on quantitative research rules. That opportunity can be achieved through transferability as a measure. The strategy for, and details pertinent to, transferability are explained in the methodological rigour section.

3.15 Summary

In this chapter I have presented the methodological approaches adopted in order to carry out this study. I began with the research aim and questions, and then followed by setting out the justification of adopted methodology. Focused ethnography was chosen as the data gathering methodology for this study, because it enabled me to gain an in-depth ‘thick’ understanding about families’ experiences in their real setting. I was also able to interact with the participants for six months, which then gave me an in-depth picture of the families and their lives. Data analysis has been explained in this chapter, which leads to the study’s findings being presented in the next chapter.

4 Family Profiles

4.1 Introduction

In this chapter I present the families' profiles. In ethnographic studies, providing details of the basis of the information and the setting for the ethnographic fieldwork are very important. In this chapter, the family profiles are described to provide an understanding of the overall context. Data obtained from interviews, and notes made during the fieldwork (the fieldnotes) are presented to illustrate the researcher has explored the participants' social worlds. Including the raw data will give an opportunity for others to make judgments about the authenticity, transferability and trustworthiness of the findings. This research data was collected from February 2016 until August 2016. Family profiles are the result of assessment using the Friedman Family Assessment Model (FFAM), a research tool created by Friedman (2003). Building from research objective to set out the families' experiences in hypertension control in Denpasar, following research questions were developed:

1. In what ways do family members experience the impact of an individual living with hypertension within a family group?
2. How do family members experience the management of an individual's hypertension control within the family group?
3. What are the potential facilitators for, and barriers to hypertension management in families?

To answer those questions, assessment includes development stages and history of family, environmental data, family structure, family functions and family stress, coping and adaptation. In addition to the written information, the families' profiles are also presented visually using genograms. An overview of the FFAM, its categories and a *genogram* was presented in the theoretical framework section of chapter IV.

All the written data presented here is anonymised, with pseudonyms used for all the participants, so they cannot be identified. The following sections present the families' profiles; included in the profiles are the six categories, genogram and ecomap. The genogram and ecomap symbols are presented in Figures 2 and 3.

4.2 Genogram and ecomap symbols

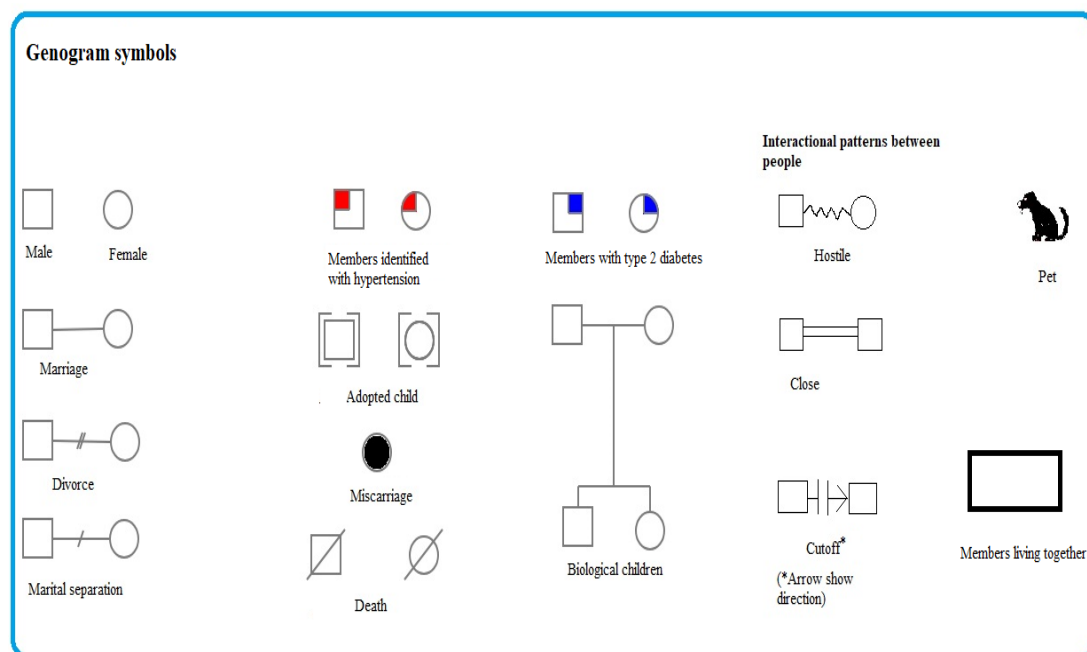


Figure 2: Genogram symbols

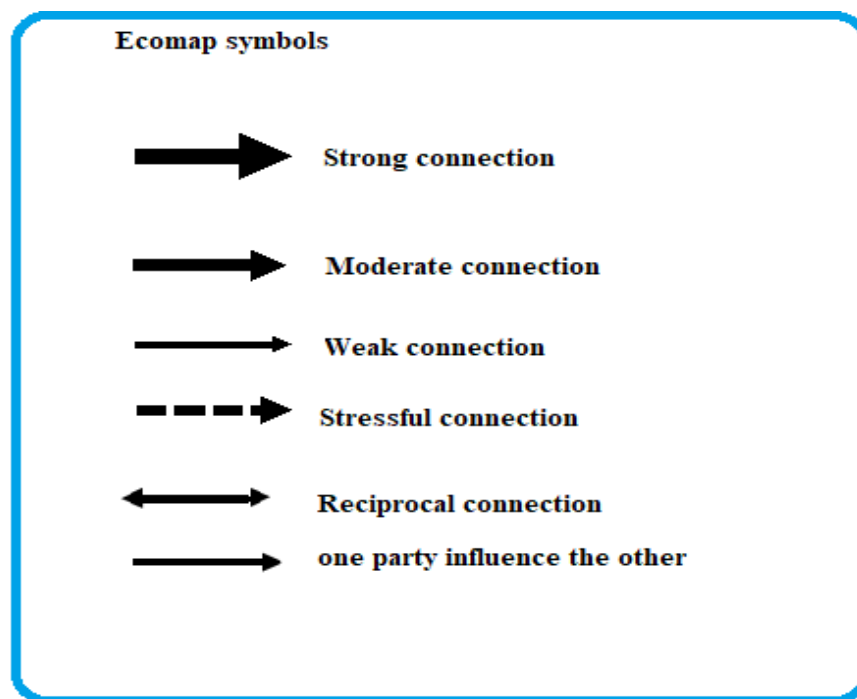


Figure 3: Ecomap symbols

4.3 Family profiles

I presented eleven family profiles below, complete with the genogram and ecomap.

4.3.1 Agung's family

4.3.1.1 Family composition

This family is a traditional extended family. The unit consists of 2 nuclear families: Raka's family and Yoga's family. The composition of this family is shown in the genogram below (see Figure 4).

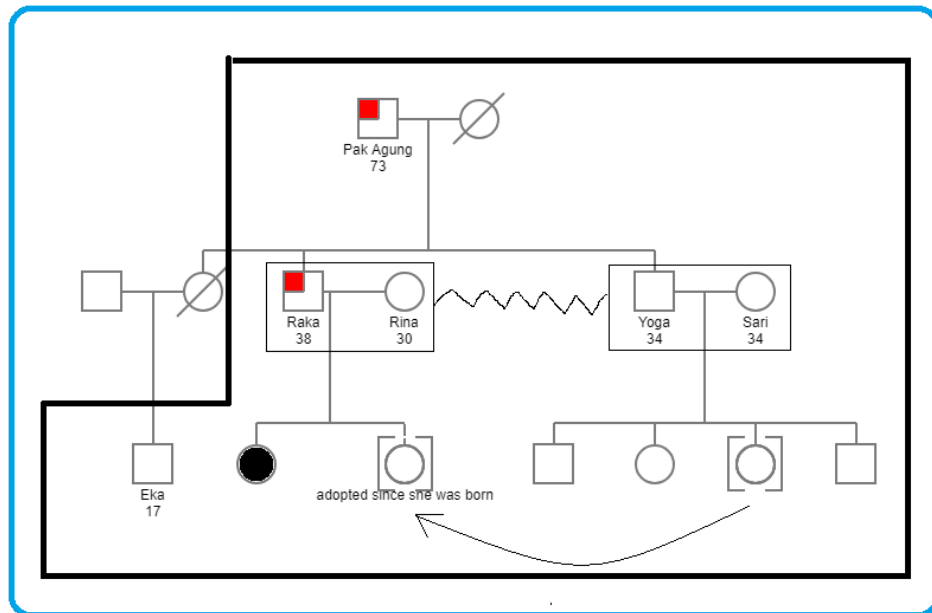


Figure 4: Agung's family genogram

At first contact, it was revealed Pak Agung is the patient with hypertension, but eventually I found that his older son has been diagnosed with hypertension too. Cardiovascular disease is the major problem in this family. Pak Agung had been identified as having hypertension since he was in his early 20s. His wife had died from a stroke, with hypertension as the aetiology, and two of her siblings had also died from cardiovascular disease. With a strong history of hypertension in the family, it seems Raka is affected by the condition because it is inherited.

This family is struggling financially, even though the household bills are shared between Raka's and Agung's families. Family finances are always a concern for the adult family members. During our conversations family members often complained about their financial situations. This situation affected how they prepare their foods. At the start of the month when Pak Agung received his pension he will cook mostly his favourite foods, mainly involving pork. However, as he runs out of money, he would eat whatever his daughter in law has prepared for the family.

As Balinese Hindu culture, every six months on Galungan day, this family slaughters a pig that is then used as an offering. The after-offerings meat is then enjoyed for several days, and usually causes Pak Agung to suffer after effects. Rina and Raka said their father usually visits the clinic after the Galungan celebration, because he starts having headaches, and it always turns out his blood pressure increases.

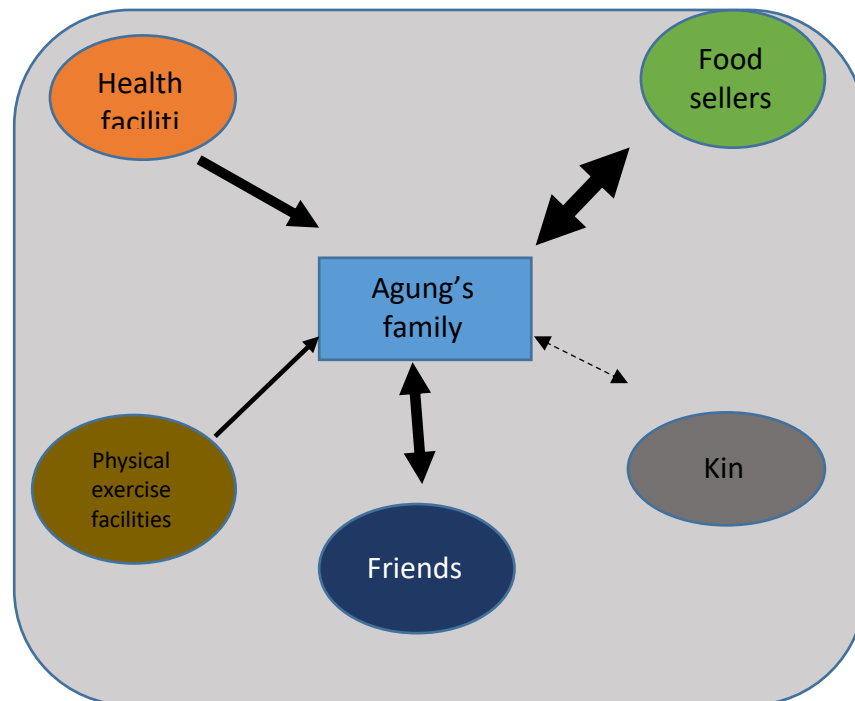
4.3.1.2 Developmental stage

Pak Agung used to be hospitalised because of his hypertension, and this sudden event worried the family. Conflicting stages of control were observed between the patient and his family. Pak Agung had reached the stage where he was controlling his blood pressure using medication, and was therefore optimistic that he had controlled his blood pressure because he always managed his symptoms. However, his family seemed pessimistic about his condition, as they argued the medication could give unwanted side effects and therefore Pak Agung would be better not taking medicine every day, but rather he should be using herbs and controlling his diet.

4.3.1.3 Environmental data

Environmental conditions have compromised Pak Agung's engagement in regular exercise. Pak Agung's family live in a house that faces a busy major road, and therefore is not a safe place to have a walk. Many cars and motorbikes use the road, and even though the road is constructed for pedestrians to use, the conditions are really poor. The surfaces are uneven; in many areas concrete is missing, and there are some big gaps that are dangerous to walk on because those faulty pathways are actually supposed to cover the sewers. Those poor conditions are the main reasons why Pak Agung and his family members prefer to ride their motorbikes wherever they go; even if it is only for a short distance. In reality riding a

motorbike is more convenient and faster, with less effort and energy needed than for walking. Also the house is relatively far from the clinics that have weekly gymnastic sessions; another reason for avoiding doing physical activities. The following ecomap (see Figure 5) depicts the relationships between Pak Agung's family and their environment.



4.3.1.4 Family structure

Pak Agung has the power to control his blood pressure. He makes the decision whether he needs to visit the clinic on regular basis, or not. However, when the symptoms appear, such as last time he fainted because of his increased blood pressure, the family takes control of his condition. The other family members would take him to hospital and ensure that he obtains proper care. The power to control his blood pressure is dynamic, depending on the symptoms he has. The communications related to his hypertension control would be around suggestions for not eating too much fat; the family would readily blame Pak Agung if he showed any symptoms.

4.3.1.5 Family functions

The family knowledge toward hypertension is poor. Pak Agung understood that he needs to take the medication regularly, but his knowledge about hypertension still lacking. He could only mention that, to him, hypertension is a headache. Raka has slightly better knowledge about hypertension but he has negative attitudes towards repeated daily medication. The daughters in law both only knew that hypertension can lead to a stroke; however, they could not mention the causes for, or the management of, hypertension. The other son, Yoga, and grandson, Eka, both only knew hypertension as the source of anger for Pak Agung and Raka. Poor knowledge about hypertension could affect the daily control of hypertension. Rina is the one who mostly cooks for her father in law, but she does not have enough knowledge to support him. As an example of this knowledge gap, she does not know if salty food could trigger hypertension. As a family with a strong history of cardiovascular disease, this family has only minimal awareness regarding hypertension. Eka is an active smoker, and Raka, who is also identified with hypertension, is not taking his medication regularly; furthermore he drinks alcohol.

4.3.1.6 Emotional expression and family response strategies

The family believed hypertension is related with anger, either the anger causes the elevation of blood pressure or the blood pressure raise creates anger. The family members mostly tried to soothe the situation when they have to face patients' emotion expression, such as anger. Yoga always avoid open argument by keep silent when he and his brother need to find a solution on a problem, because he believed the blood pressure in increasing when Raka gets angry. Even Pak Agung also avoid to argue his son (Raka) when he shows anger, because he believed it was the blood pressure increased.

4.3.2 Dony's family

4.3.2.1 Family composition

Pak Dony's family is a single parent family, since his wife passed away in 2009 due to a stroke. He lives with his teenage daughter, Dina; however, he also has another daughter and a son, who live in Jakarta. Pak Dony was very upset with his son because he did not finish his studies, thus their relationship became estranged. The following is the genogram of Pak Dony's family (see Figure 6).

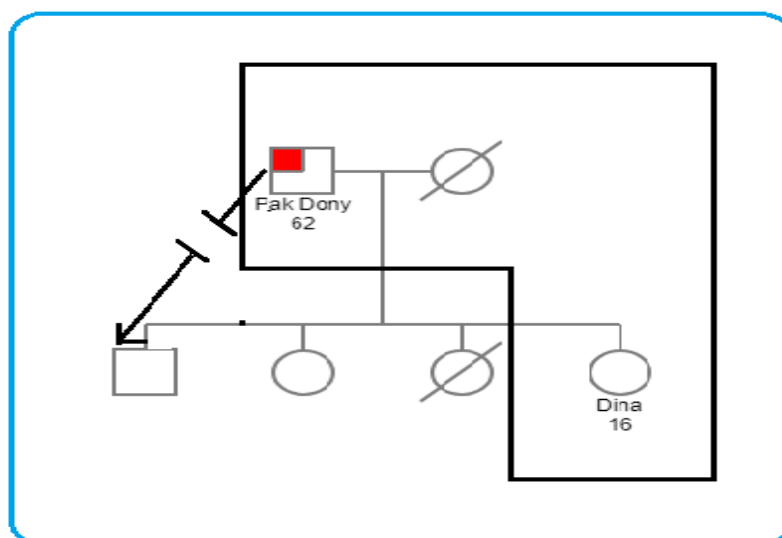


Figure 6:Dony's family genogram

When I first met him, Pak Dony talked a lot about health, medication and lifestyle. His blood pressure started to increase after the death of his wife. He reckoned his blood pressure was increasing because he was too tired after the funeral.

This family's income comes from selling food supplements. But it seemed Pak Dony earns less than he should to meet the family's needs. Pak Dony was aware of his condition, and was therefore taking medication and exercising regularly. He could not control his diets because he did not cook meals at home; instead he bought meals from the food sellers. However, he was honest enough to admit that

such a diet was probably as not as healthy as 'homemade'. His lack of diet control was informed by his financial issues; Pak Dony calculated buying meals out is much cheaper than cooking at home. Pak Dony does not have any pension that he can rely on during his old age. Dina, his youngest daughter is still in school, meaning that she still needs supporting financially. As Pak Dony and his son are not communicating the father can only ask for help from his elder daughter; although that assistance is not always forthcoming.

Attending social gathering and religious events are also a challenge for Pak Dony, because he cannot resist eating the fatty and salty foods that are always available. On those occasions he would enjoy his favourite foods, which are various meats, that he could not have every day. He said after attending those occasions, he would not eat meats for several days.

4.3.2.2 Developmental stage

Pak Dony was at the stage of maintaining normal blood pressure and the family supported that. He had been controlling his blood pressure since he was diagnosed in 2009. This was confirmed when he said he would keep his blood pressure within a normal range because he does not want to have a stroke. Pak Dony aware he has inherited the condition from his parents; he knew the impact of untreated hypertension, so therefore he always took his medication and exercise regularly. He mentioned that his family has a history of high blood pressure; therefore, he could not prevent himself from getting the disease, but he could guard against the further impacts of hypertension, especially a stroke. Since the beginning of his diagnosis for hypertension he has taken his condition very seriously. He used to measure his blood pressure every day, but the device broke so he had to stop. Pak Dony was able to maintain his blood pressure in a normal range by taking medication and exercising regularly, but the main challenge for his hypertension

control was his diets. His daughter would take part in his hypertension management only when he showed symptoms. If Pak Dony experienced extreme blood pressure elevation, then Dina would go to buy the medication, or whatever his father needed.

4.3.2.3 Environmental data

There are external factors that influenced Pak Dony's hypertension control performance, including his physical and social environments. Pak Dony's family live in a neighbourhood that is close to the clinic and park; thus the physical environment provides positive support in shaping his habits to do regular exercise. He rides a motorbike, so he does not have any issues about reaching the clinic for regular check-ups, and he can just walk to the park for his exercise. He is also very close socially to his neighbours, they sometimes exercise together in the park. However, there are also negative influences from the environment that may shape the family's patterns in food preparation. There were some food sellers nearby, and for the family they were the saviours of their daily lives, because the foods are cheaper rather than the home cook foods. However, these circumstances inevitably shaped the food patterns for the family. First, the foods may not be beneficial for the family health, due to the quantity being far from enough for the family's members. Second, the salt and fat used in the food's preparation are not controlled by the customer, which may negatively affect Pak Dony's blood pressure. The family's diets were also influenced by their social network during religious events, where food plays a very important role. Pak Dony would particularly enjoy the foods that were rich in fat when he attended the social gatherings, and he was fully aware of that. The following ecomap (see Figure 7) depicts the family's relationships with their environment.

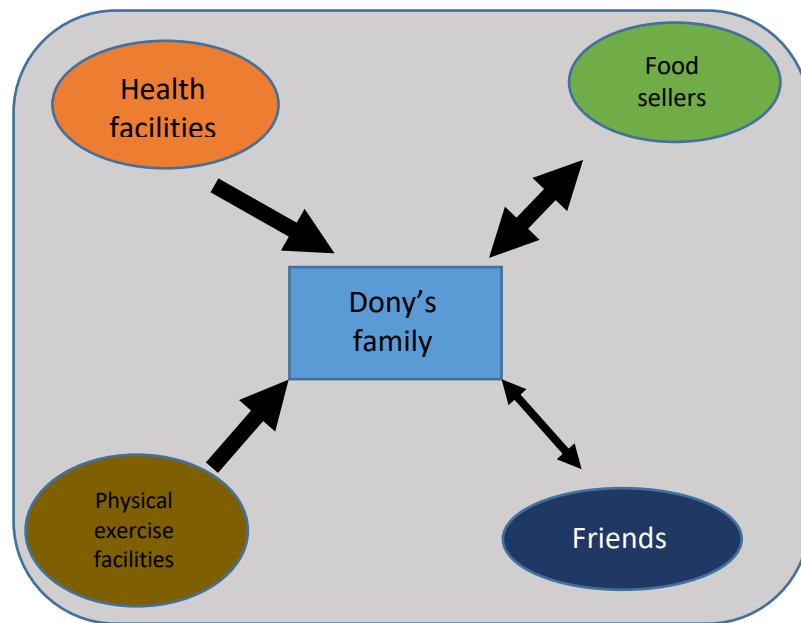


Figure 7: Dony's family ecomap

4.3.2.4 Family structure

Pak Dony made all decisions regarding his treatment; he understood what he had to do to manage his condition. Dina only helped her father when he needed assistance. For example, when Pak Dony experienced an emergency because his blood pressure suddenly increased, he asked Dina to go to buy the medication. Dina said she knew about hypertension but she believed her father knew more about the condition than she did. For this reason she did not really involve herself in her father's treatment. However, Pak Dony appeared to show little control over his diets; instead he would just enjoy the foods from the stalls and whatever was available during the many social gatherings he attended.

4.3.2.5 Family functions

Pak Dony had adequate knowledge about his condition and its treatment, so he took on the responsibility for managing his own condition., Dina, his daughter, was also aware of his condition but she did not get involved in his daily care,

although she revealed her concerns after she witnessed two emergency situations, in which Pak Dony's systolic blood pressure increased to almost 200mmHg. When the father was not showing any symptoms, Dina would think her father is doing fine. As a single parent, Pak Dony had to take care of Dina by himself and with her stage of development as a teenager, he was at times potentially overwhelmed by all her drastically changed behaviour, and mood swings. This single-parent situation could be a stressor for him, particularly as he does not have anybody to assist him raising his teenage daughter, since his wife passed away because of stroke.

4.3.2.6 Emotional expression and family response strategies

Pak Dony's stressors mainly come from financial condition and his children. Financially because he could not earn as much as before and he is getting older, so may not be as energetic as before. Meanwhile his children causes of stress. First there is Pak Dony's argument with, and split from, his son; they no longer communicate with each other. Unresolved problems have been known as significant causes of psychological distress and associated psychosomatic disorders (Thoits, 1994, Thoits, 2006). Another cause of stress is Dina, his teenage daughter; he was upset when she asked permission to go out with her male friend. He expressed his emotion to me, and I assumed he did not have much support to whom he could share his problems, especially when the the elder daughter too far away and his poor relationship with his eldest son.

4.3.3 Joko's family

4.3.3.1 Family composition

This unit is an augmented family, where Pak Joko and his wife (Bu Rena) live with four other people that they considered as their family. One of them is eight

years old (Romeo); he has just moved in house because his parents live in another city. Pak Joko didn't want him to be included as a participant because he was very new to the family. There are three other adult males that I have included as participants because they were also living with this family. They are Arya, Bima, and Sena. The following is the genogram of Pak Joko's family (see Figure 8):

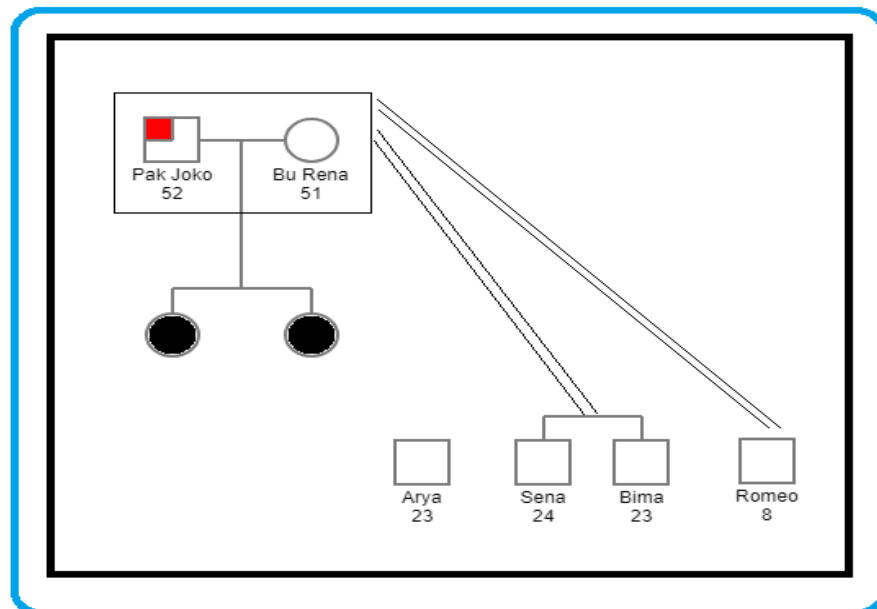


Figure 8: Joko's family genogram

4.3.3.2 Developmental stage

Pak Joko was at the stage trying to maintain the habits, especially in taking the medication, as when I met this family for the first time, Pak Joko had just started to take his medication regularly. He used to ignore the medication, until one day he fainted due to hypertension; since then he has started taking the medication. However, even now he sometimes forgot to take it, but luckily Bu Rena always reminds him to take his medicine. Bu Rena is also the one who reminds Pak Joko to avoid eating too much meat; she is 'the police' as Bu Rena calls her. His friends and relatives have always supported him as he tries to control his blood pressure.

This support indicated that his social networks were available for him to help and encourage his hypertension control. Pak Joko's main intervention to control his hypertension was taking the medication; however, he showed little interest or concern with issues relating to physical exercise or diets. The future challenge of his blood pressure control would be to ensure he takes his medication on a regular basis; particularly problematic when he has to go away for a work trip without his wife.

4.3.3.3 Environmental data

The physical environment influences the ability to take physical exercise. This family lives in the central district of Denpasar, so they can easily reach the clinic and park by motorbike. However, even though they live near the park Pak Joko could not go regularly, because he had to help his wife in preparing food for the catering. This family running a seasonal catering business, and they had orders during my visits to their homes. When they had more free time Pak Joko and his wife would go to the park and exercise together, but since the catering orders are increasing, they do not have time to go. They live in the most crowded neighbourhood in Denpasar, with poor pathway conditions, and this potentially discourages Pak Joko from doing any exercise which does not involve the park. Their proximity to the clinic, and the services that are provided for free, are the external support for this family in controlling Pak Joko's blood pressure issue. Although he was eligible to join the weekly exercise at the clinic, Pak Joko said he did not know about this activity. The following ecomap (see Figure 9) illustrates this family's relationships with the external environment.

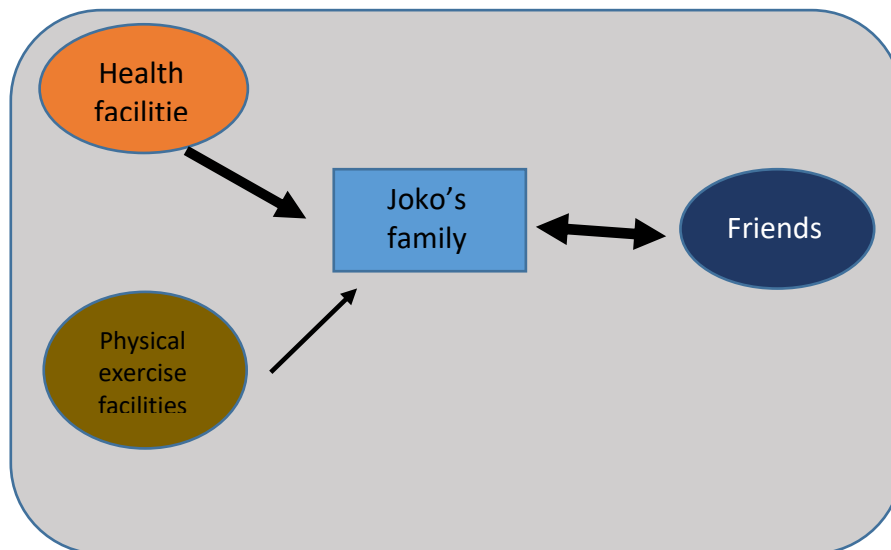


Figure 9: Joko's family ecomap

4.3.3.4 Family structure

The power in the family for making decision in hypertension control-related activities was dynamic. For example, Pak Joko as the head of family was predominant in decision making for that family, but for the food and diets Bu Rena had more power to decide the food preparation in daily life. Another example, Pak Joko wanted to go for exercise but had to cancel the idea because his wife needed his help to run the catering. The family's finances are far more important than going to the park for exercise.

4.3.3.5 Family functions

Both Pak Joko and Bu Rena considered hypertension is a life-threatening condition. She considered hypertension is life-threatening because Pak Joko previously experienced an increasing blood pressure that caused him fainted. Bu Rena worried if her husband was going to experience another emergency situation like he had in the past. Thus she always reminded him to take his medication. They were aware of the impact of hypertension, such as a stroke, because they have a

friend who had a stroke as a result of hypertension that was left untreated. Bu Rena was also concerned about her husband's diets, especially when they attend social gatherings. Especially on such occasions she reminds her husband "to eat less meat!" Bu Rena has more control over Pak Joko's hypertension management, both when he does not have his symptoms and even more so when he does.

4.3.3.6 Emotional expression and family response strategies

This couple always share and solve their problem together. They have many friends that often come to visit them, and help who help Pak Joko to manage his stress. Pak Joko also sometimes joins Bima and Sena playing a guitar and they would sing together. So, any stress is managed by sharing problems with the other family members or friends.

4.3.4 Gatot's family

4.3.4.1 Family composition

This family consists of Pak Gatot, Bu Lely (his wife), Bintang (their daughter), three grandsons and Darto (Bintang's husband). I met Bu Lely and Pak Gatot at the *Puskesmas* when they attended the weekly gymnastic activity. The physician at *Puskesmas* asked me to approach Bu Lely because she suffers hypertension without any other chronic conditions. The genogram (see Figure 10) illustrates Gatot's family. Pak Gatot has a son who lives with his family close to Pak Gatot's, and he was included as a participant.

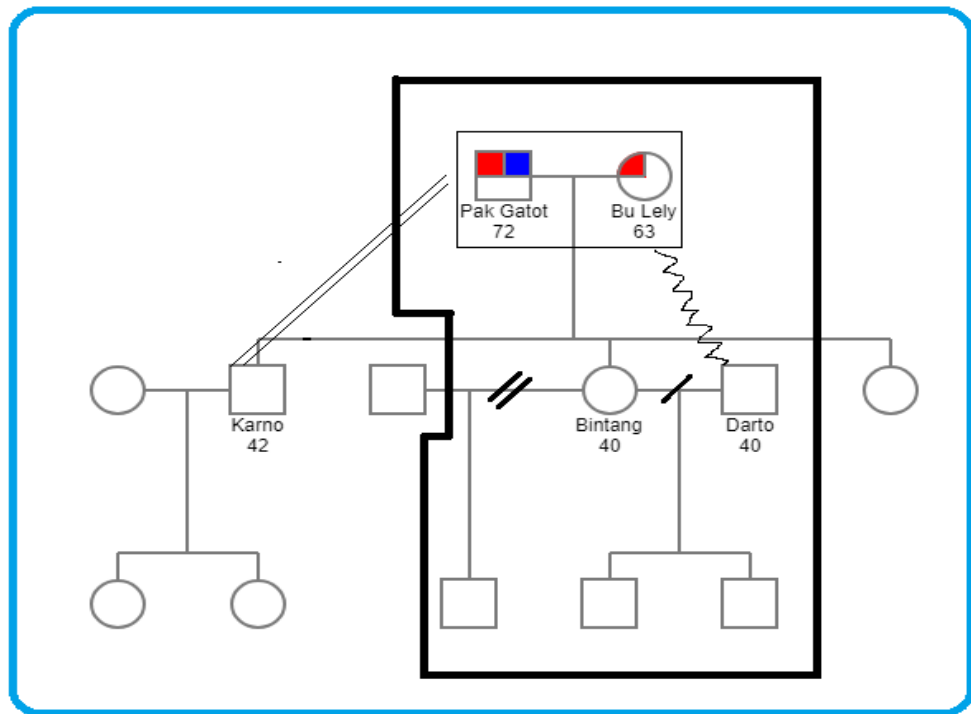


Figure 10: Gatot's family genogram

Pak Gatot and Bu Lely both have hypertension, but Pak Gatot has it in combinations with diabetes. The highlight of the genogram is Pak Gatot's and Bu Lely's conflicts or disagreements with the son in law (Darto). Both Bu Lely and Pak Gatot confirmed that their daughter and her husband were experiencing family issues. This problem was a significant stressor for Bu Lely and Pak Gatot.

4.3.4.2 Developmental stage

Pak Gatot and Bu Lely were at a stage when they thought it appropriate to control their hypertension by taking their medication on a regular basis. They also joined the weekly gymnastic activity at *Puskesmas*. Bu Lely used to be generally sceptical about any and all medications used for for hypertension management, because of her concerns about the potential side effects. However, the weekly activity had changed her perception toward hypertension drugs. The challenge this couple might face is the inconsistency of medication supplies available in *Puskesmas*.

4.3.4.3 Environmental data

The physical and social environment has been a huge support for the family in controlling the issue of blood pressure. This couple live in a very dense area, but the clinic is within walking distance, so they can easily reach it. Their neighbourhood has a park that also holds weekly exercise sessions for all residents. A social unit called *banjar* also regularly held exercises for the elderly, but it was mainly the women who got involved in this activity. In general for physical exercise and healthcare services this couple did not find any difficulties, because the physical and social environment supported them for those activities extremely well. The family members were also glad and very supportive that their parents were involved in the exercise sessions provided by the clinic and *banjar*. Karno, the son, mentioned that he felt the regular activities at the clinic were very useful for his parents. He would not mind helping his parents to reach or access the health services if they needed such support. The ecomap in Figure 11 illustrates this family's relation with the environment.

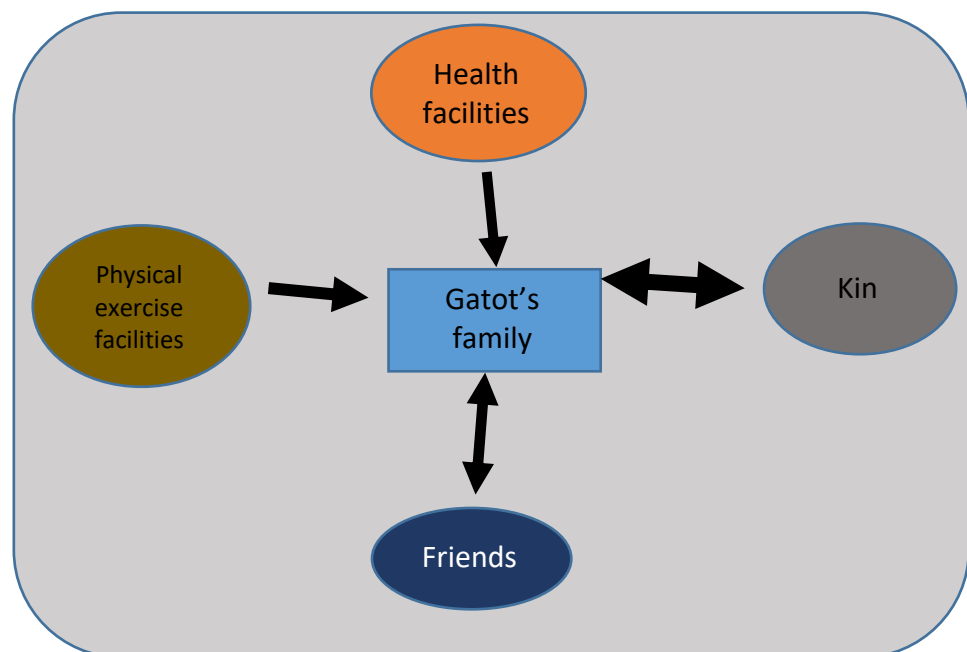


Figure 11: Gatot's family ecomap

4.3.4.4 Family structure

Bu Lely and Pak Gatot are mutually committed and supportive regarding the taking of their medication and doing their physical exercises. They are a couple who always enthusiastically go together to the clinic and are very supportive towards each other. However, sometimes they could not avoid family issues that became significant stressors for them, with the potential to negatively affect their blood pressures. In addition, the family also influenced the diets and food preparation. During such meal preparation activities, the priorities moved away from Bu Lely and her husband to focus on the grandchildren. Even though Bu Lely cooked for the family, she would normally prepare what her grandchildren requested to eat. They were fond of fried food which, due to the oils and fat involved, was not a very healthy diet for hypertension patients (Astrup et al., 2011, Harika et al., 2013).

Family functions

Both Bu Lely and Pak Gatot acknowledged the regular medication taking would prevent them from having strokes, and so did their family members. As long as they continued taking the medication everything was going to be alright. However the family members may not have been aware that stress also increases the blood pressure, so they appeared not to know if any of the family's issues will affect Pak Gatot's and Bu Lely's health. As reported Pak Gatot's son, Karno, expressed his concerns relating to his parents' hypertension. He always tried to make them happy, and avoided burdening them with his problems.

4.3.4.5 Emotional expression and family response strategies

One day, when I visited the family, their daughter (Bintang) was having issues with her husband. Bintang's problem apparently had a strong impact to Bu Lely and Pak Gatot. Bu Lely believed that the problem had changed her vital signs. The fact that they could not see their grandson every day had hit them the most. The other challenge resulted from the problem was when the wider family circle knew about

their issues. They could not hide the problems from their relatives, and this matter was a significant extra burden for them. They felt angry and upset with all the problems, but as Javanese they were culturally obliged to keep the situation 'low and steady' and avoid any conflict with their daughter and son in law, in order to establish and maintain harmony in their family.

4.3.5 Sadu's family

4.3.5.1 Family composition

Pak Sadu is a hypertension patient. He lives with his wife Bu Marni, who is suffering from diabetes. They had four daughters, but the 2nd daughter passed away when she was two days old. The first daughter lives in a rented house and runs a food stall near a hospital. The third daughter lives nearby with her husband and children. She runs a small soya milk enterprise from home. The last daughter lives in another part of the city, studying and working as a costumer service agent in a cellular company. The first daughter is divorced without children; the third daughter is married with three children and the last one is still single and lives in a different house. The complete picture of this family is presented in this genogram (see Figure 12).

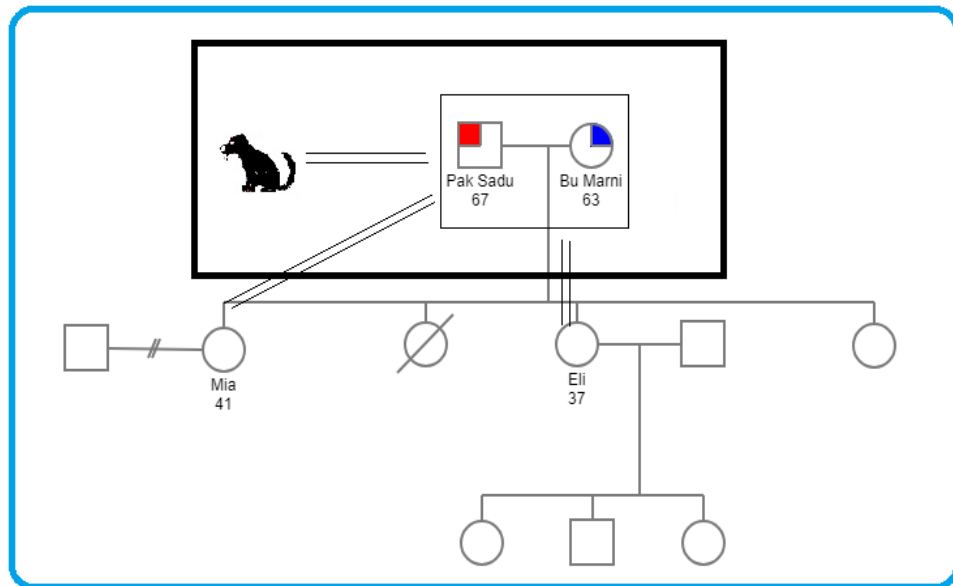


Figure 12: Sadu's family genogram

4.3.5.2 Developmental stage

This family is at the point where they have decided to control and manage their blood pressure and diabetes related issues. Both Pak Sadu and Bu Marni used to ignore their disease management; Pak Sadu is the one with hypertension, while his wife was identified as having diabetes. Since they joined the weekly group at *Puskesmas*, he and Bu Marni have started taking their medications and are now exercising regularly. Pak Sadu was fully aware that hypertension cannot and must not be underestimated, because it can be a silent killer. The challenge for this family mainly comes from their diets, because they mostly buy their food from the food stalls.

4.3.5.3 Environmental data

The neighbourhood of this family provides both positive and negative influences. The positive influence for this family is that the clinic and park were very accessible, so they did not have any difficulty obtaining health services and doing

their exercising. However, the negative influence is related to the easy access of affordable cooked foods in their neighbourhood. They live in an area that is surrounded by food sellers displaying various food options. This convenient situation has strongly influenced their lifestyles, as they all prefer to buy cooked foods from the stalls rather than prepare meals at home. However, affordable foods not necessarily healthy foods; their quick and easy diet may compromise their health, as such foods are high in salt and fat, ingredients that would definitely negatively affect Pak Sadu's blood pressure. The following ecomap (see Figure 13) depicts this family's relationships with their environment.

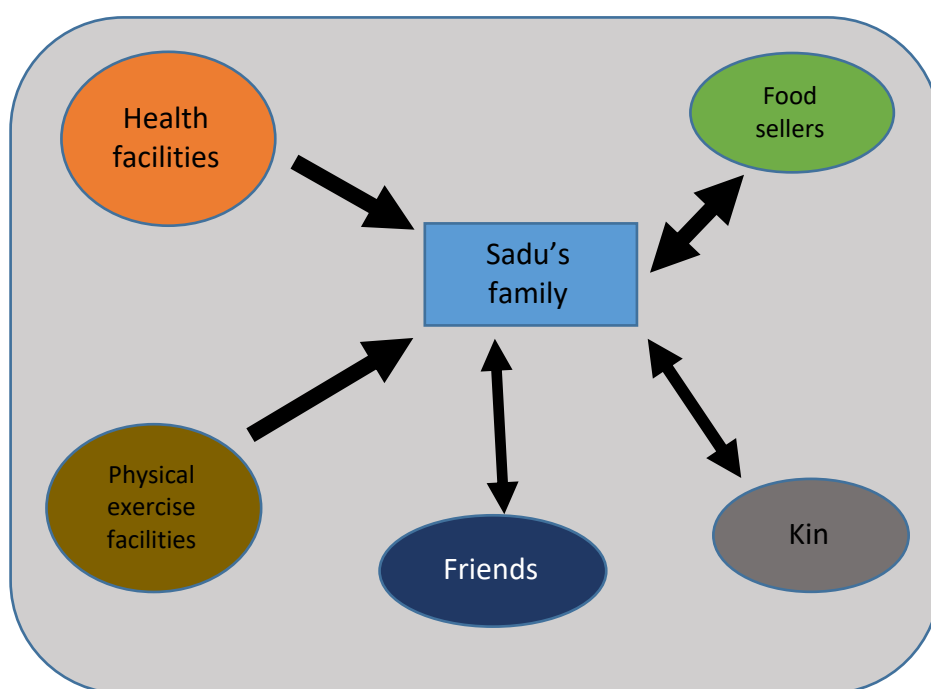


Figure 13: Sadu's family ecomap

4.3.5.4 Family structure

The weekly activities at the clinic have developed an awareness of ways to prevent the adverse impact of hypertension. Pak Sadu was mainly controlling his hypertension by taking the medication regularly. This husband and wife couple have been supporting each other in managing their condition. They attend various

exercise events together, always remind each other to take their medication and have regular check-ups at the *Puskesmas*. However, even though they kept mentioning that the blood pressure issue had been controlled, they appear to lack concern for accessing healthy diets because this family continues to buy its meals from the food sellers near their home. As mentioned above the environment has negatively influenced them over the matter of diet control in order to manage their hypertension.

4.3.5.5 Family functions

Hypertension management was mostly performed by Pak Sadu and his wife. This couple supported each other in controlling their diseases, especially regarding taking their medication and doing their exercises. The daughters were fully aware of their father's hypertension, but they could not watch him every day, so they mostly assisted in providing financial aid, in cases when they were required to buy medications or to meet other necessary urgent expenses. They did not try to get involved in their parent's treatment, because they assumed their parents knew more about the treatment than they did.

4.3.5.6 Emotional expression and family response strategies

The family believed that when Pak Sadu was stressed it made him angry, and that anger would then increase his blood pressure even more. Thus the family always try to keep the situation in the house as calm as possible; they preferred to use avoidance strategies when Pak Sadu was feeling angry. An avoidance strategy is a strategy where those individuals involved in a situation would avoid making any arguments. Bu Marni would avoid her husband in order to let him calm, or would very gently remind him to be calm. Other than avoidance, this family also created a calm situation by not disclosing their problems to Pak Sadu. One of the daughters

preferred to keep her problems to herself and so she moved out in order to maintain a sense of calm in her parents' house, thereby ensuring minimal stress for Pak Sadu. She aware her father would excessively think about a problem which then caused his blood pressure to rise, so she decided to prevent that from happening by removing herself from his immediate environment.

4.3.6 Wimar's family

4.3.6.1 Family composition

Pak Wimar is a 65 years old who suffers from hypertension. He lives in a house with: a) his wife Bu Puri, who is 53 years old and works as a nurse; b) two daughters : Rumi (aged 30) and Rita (aged 23); c) two grandsons (5 and 3 years old), and a servant (Bu Mona). The genogram below depicts Pak Wimar's family members (Figure 14).

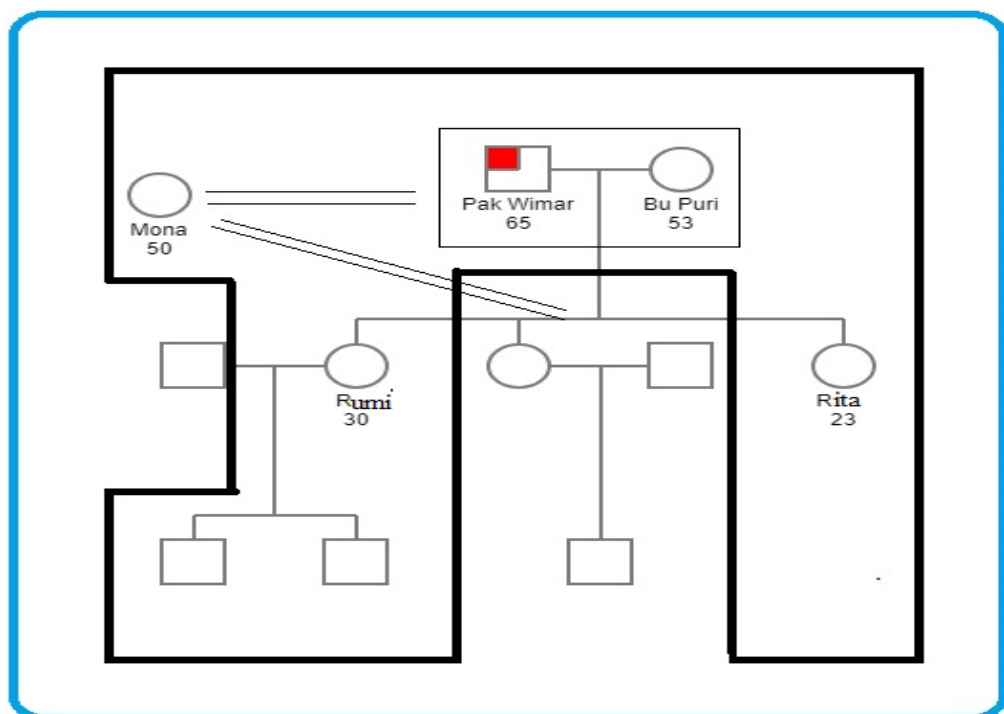


Figure 14: Wimar's family genogram

4.3.6.2 Developmental stage

Pak Wimar's family was at stage in their condition where they wanted to quit their medication, because Pak Wimar felt he no longer had any symptoms that indicated hypertension. Thus, he thought his stopping the medication would not be a problem. Even though both Bu Puri and Rumi were nurses, and therefore theoretically 'should know better' Pak Wimar was supported by Bu Puri, and certainly not challenged by Rumi, regarding his wish to stop taking his medication. Therefore I was able to conclude that continuing taking the anti-hypertension medication was the main challenge for this family, because even the family members who worked as health staff, but they tend to support Pak Wimar to quit the medication.

4.3.6.3 Environmental data

Pak Wimar's family has not used the facilities available nearby. Pak Wimar lives close to both a clinic and a park. However, he rarely went to the park for exercising. The neighbourhood was not a safe place for exercising, such as for jogging, because the streets were very narrow and busy with both cars and motorbikes. The family sometimes used to go to the park together for exercising, but they rarely did it anymore because they were busy with their work. Meanwhile, Pak Wimar actually had the chance to do regular exercise with the elderly group in his hometown, which was not too far from where the family lived, but he rarely attends this activity anymore because basically he had lost interest in doing so. Ecomap below illustrates this family relation with the environment (see Figure 15).

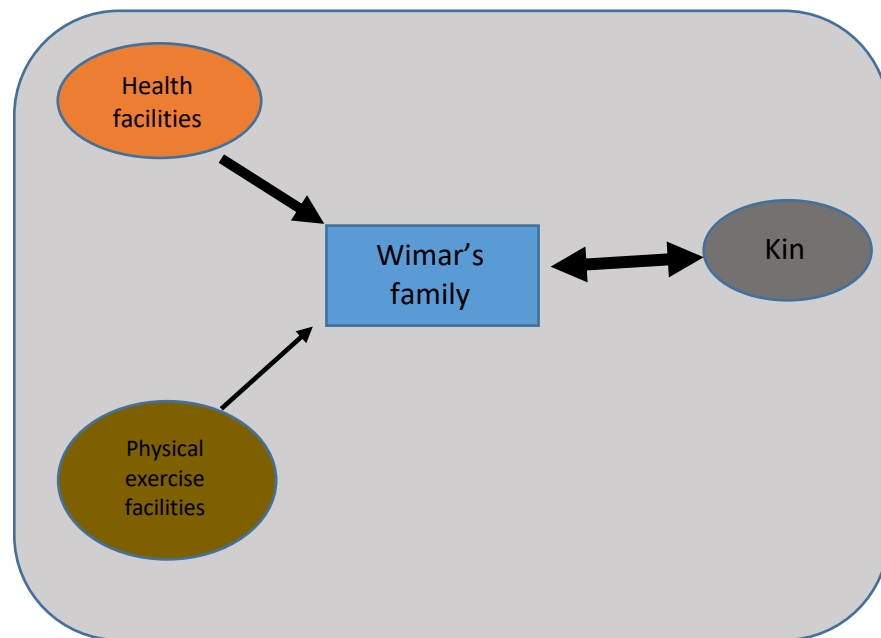


Figure 15: Wimar's family ecomap

4.3.6.4 Family structure

Pak Wimar has the power to control his medication, but his wife has more control on diets. This power distribution was evident when he asked his wife to use less oil in the soup; the wife insisted that was how the soup should be cooked, so then he stopped complaining. The daughters usually only asked about their father's health status after his regular check at *Puskesmas*. They rarely got involved in their father's hypertension control.

4.3.6.5 Family functions

The family was aware that hypertension can cause a stroke, and mentioned to me that taking medication regularly could reduce the risk. Although Bu Puri supported her husband's wish quit taking his medication, she was always very caring in that she also made sure he took his medication regularly. Their daughters also showed support for Pak Wimar, such as Rumi always ensured her father had a

sufficient supply of his medication. The other daughter (Rita) bought a pair of shoes for her father, so he would go for exercise more often.

4.3.6.6 Emotional expression and family response strategies

Their strategy to reduce stress involved around sharing their problems with the other family members; therefore, gathering with the family members was one of their main ways to reduce stress. This family usually came together at their home in the village where they would meet their other relatives. For Pak Wimar, the family is his main support for stress management, especially his grandchildren. This family showed a very cohesive relationship, and its members were very supportive of each other. The children said their father was a really relaxed person, who rarely became stressed or angry.

4.3.7 Jono's family

4.3.7.1 Family composition

Pak Jono is a hypertension patient. He lives with his wife Bu Karti, his daughter Mila, two grandsons and a son in law. Jono's family is illustrated in the genogram below (see Figure 16).

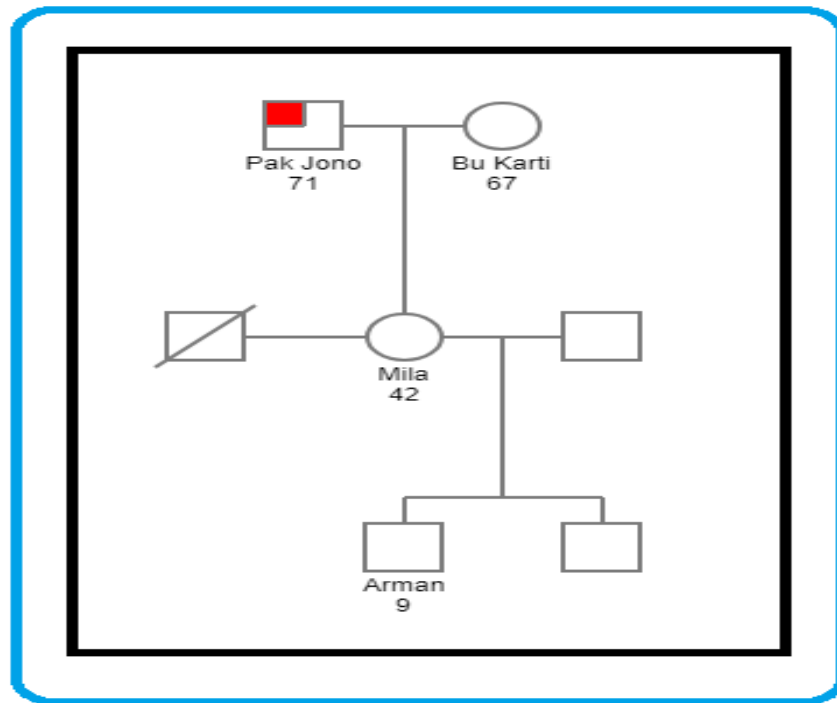


Figure 16: Jono's family genogram

4.3.7.2 Developmental stage

Pak Jono was able to maintain his blood pressure within the normal range (120/90mmHg). His family and the clinic agreed that Pak Jono has always maintained his blood pressure within that range, has regularly taken his medication, and goes for his blood pressure checks as required. Bu Karti admitted that her husband always ensures his blood pressure is not more than the normal range. However, she disagreed about the number because she believed that at their age it is acceptable to have a maximum blood pressure of 140/90 mmHg. She made it clear that she really appreciated her husband's efforts to maintain his blood pressure at the correct level. The *Puskesmas* also appreciated Pak Jono's efforts in maintaining his blood pressure, to the extent that he had achieved awards from the clinic for his diligence. However, the challenge for this family in controlling hypertension is the patient's sleep pattern; Pak Jono has to produce soya milk every

day and so he gets up at midnight to grind the soya. Chronic sleep deprivation can be related to increased blood pressure; an outcome which would not appear to be the case with Pak Jono (Ana et al., 2013, Calhoun and Harding, 2010, Choudhary et al., 2017).

4.3.7.3 Environmental data

The physical environment has benefited this family. They live close to the *Puskesmas*, and Pak Jono usually walks to the clinic for his regular checks. The family members said the clinic is very convenient for them; sometimes they can drive him to the clinic and he can just walk back home after his appointment without any issues. A park is also near his house, although he prefers to do his exercises at home. He lives in a house complex that has a big yard. Most often, that was the place for exercising. The family members usually remind him to do his exercises, even though they are just a light programme; offering him encouragement as they think it helps Pak Jono to control his blood pressure. Environmental conditions were not creating any problems for this family in their attempts to manage their hypertension at home. The family's relationships with the external environment are illustrated in the ecomap (see Figure 17)

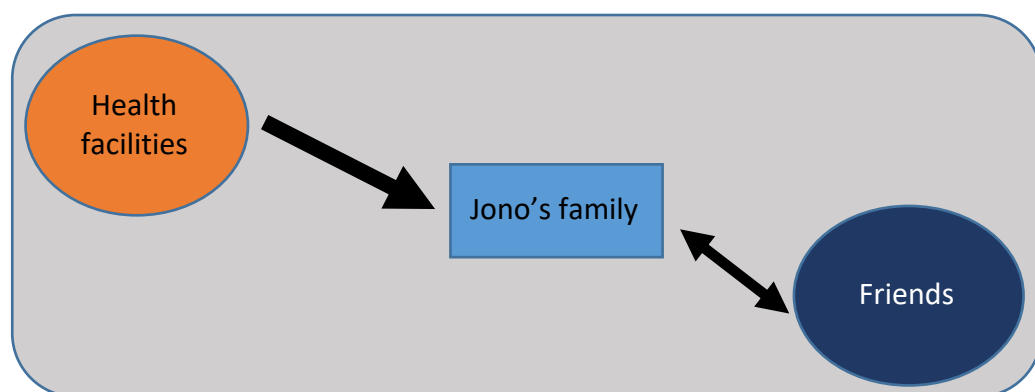


Figure 17: Jono's family ecomap

4.3.7.4 Family structure

The family members have significant influence on Pak Jono's hypertension control. Even though Pak Jono has the control of his medication, diets are controlled by his wife. The wife would prepare healthier meals for her husband, such as reducing the salt content, when he showed any symptoms of hypertension, such as headache. When Pak Jono did not show any symptoms, Bu Karti would cook as usual without worrying about the salt. The production of soya milk also disrupted his night-long sleep, because he had to get up at midnight to 'start work'.

4.3.7.5 Family functions

The family has adequate knowledge about hypertension. They were worried Pak Jono might experience a stroke. The family encouraged Pak Jono to have a better rest, because he might need more sleep after he done his job grinding the soya beans. Bu Karti's role in preparing their meals was also very important, even though it was inconsistent.

4.3.7.6 Emotional expression and family response strategies

Strategies used by the family for managing stress usually involved sharing their problems with the other family members, although they also helped each other when one of them was experiencing problems. They also have good, close relationships with their neighbours, and almost every afternoon the neighbours come over for a chat, sharing information and asking for suggestions and advice from Bu Karti, especially related to cooking because she is the acknowledged expert in that field. This activity was also enjoyed by the family because sometimes the neighbours helped them to solve their own problems. Other than sharing problems, going for holidays is a stress reducing strategy, especially for Pak Jono. The family usually arrange a trip to visit their relatives in Java and Lombok. The last trip they had was visiting Pak Jono's son who resides in Lombok, and this trip was arranged

by Mila, as a reward for her parents because they had helped her with the soya milk business.

4.3.8 Hendra's family

4.3.8.1 Family composition

Pak Hendra lives with his wife: Ibu Maya, a daughter: Wina, son in law: Gama, and two grandsons. Pak Hendra and Bu Maya have two daughters. The first daughter Wina lives in the house with her husband (Gama) and two sons. The second daughter lives in her husband's house and has two daughters. Four of Pak Hendra's siblings died when they were very young, and Pak Hendra did not know the reasons why, although he thought one of his brothers died as a result of kidney disease. One of his sisters has an abnormality affecting her eyebrows. Interestingly, Pak Hendra explains the reason for his sister's case as being the result of black magic. The genogram below illustrates Hendra's family (see Figure 18).

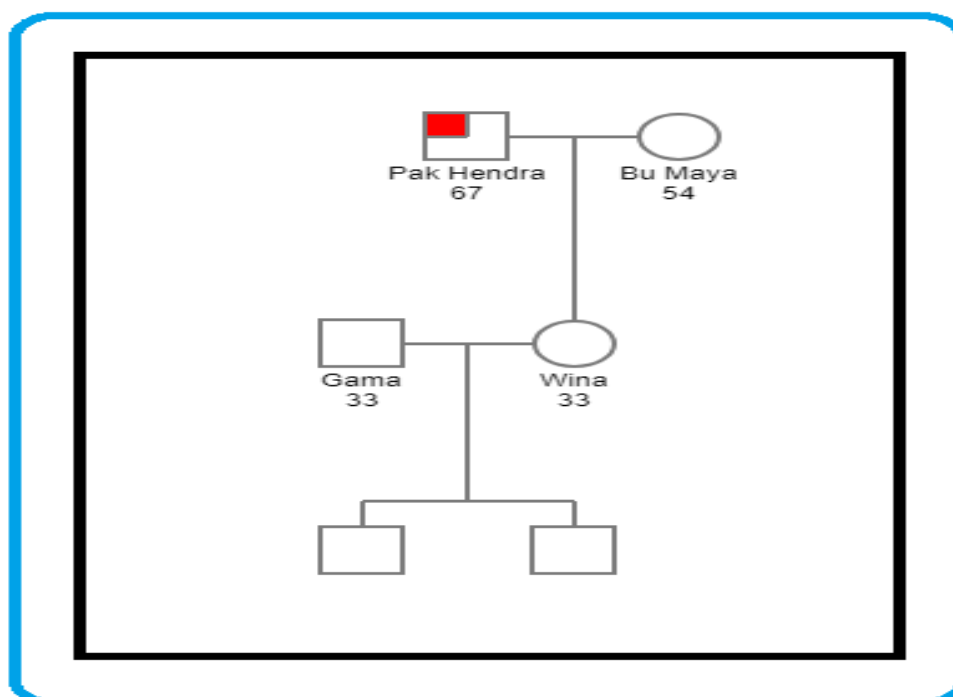


Figure 18: Hendra's family genogram

4.3.8.2 Developmental stage

Pak Hendra was at the stage in his hypertension management of trying to maintain the required good habits. Pak Hendra checked his blood pressure every week although, for his medication, he sometimes forgot to take it. Meanwhile, he did not give much attention to the complementary issues of physical exercise and diets. His reason to not getting involved in any regular-group activities was because he could not manage the time to come regularly. This issue could be a challenge for him, in his efforts to control his blood pressure.

4.3.8.3 Environmental data

Environmental factors can be a negative influence for this family when it comes to implementing their hypertension control. This family lives quite a distance from the *Puskesmas*, roughly around 3 kilometres away from their house, and there were no parks for regular exercise near their house. In fact there is a *Puskesmas* that is very close to their house, but they were registered in another *Puskesmas* that is quite far from their house. The issue of distance potentially influenced Pak Hendra in how he managed his blood pressure. In one of our conversation Pak Hendra said sometimes he did not take the medication because he did not have time to go to *Puskesmas*, because he was too busy. He mentioned that he should have joined the weekly activities at the clinic or *banjar*, but again, they did not fit in with his free time, as sometimes his colleagues would need him to go to some temples. Thus, even though he did not join any planned exercise activities, according to his family Pak Hendra usually exercising at home doing yoga. It was noted that his yoga initiative was not strictly scheduled to time of day, duration or sessions per week. He would do it when he had the time, when he had the motivation and when he remembered. The family members may not aware that their environment may affect Pak Hendra's efforts at controlling his blood pressure. His wife thinks he would go to

the clinic when he needs it, but taking medication actually is not the only way to control blood pressure. The environmental factors that may influence Pak Hendra include distance and his colleagues' demands, illustrated in Figure 19 below.

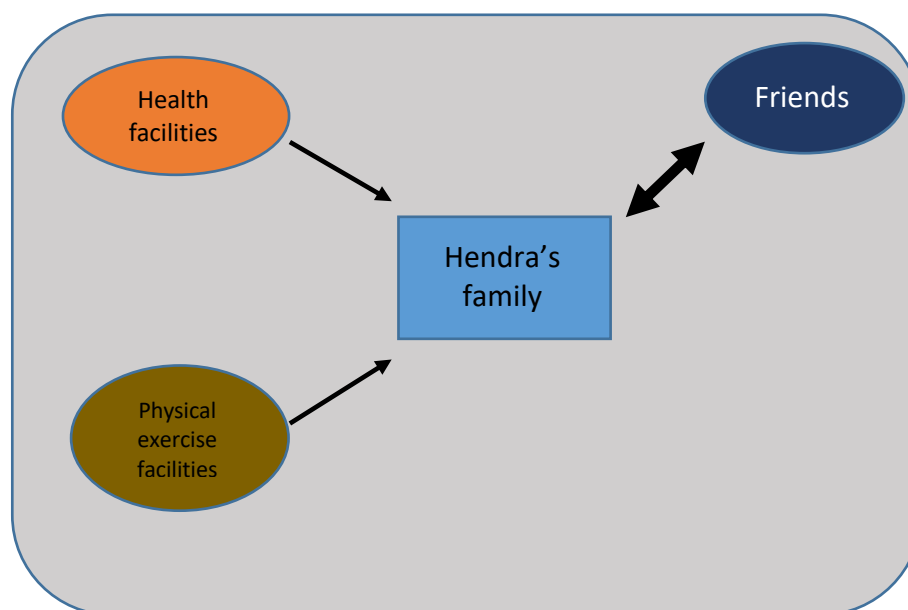


Figure 19: Hendra's family ecomap

4.3.8.4 Family structure

For the medication Pak Hendra has the freedom to maintain his habit of taking it regularly, but his diets and stress were strongly influenced by the other family members. His wife and/ or daughter usually prepare the foods for the whole family, although Bu Maya and Wina said they always cook foods that would not be excluded from anti- hypertension diets. As for stress, the family seems to have caused a significant impact on his stress levels. The members believed that taking care of the grandchildren had caused him to experience stress and had therefore raised his blood pressure.

4.3.8.5 Family functions

The family always make an effort to provide a calm environment around Pak Hendra. The wife and daughter believed since Pak Hendra took care of his grandchildren his blood pressure started to increas. Thus, when Pak Hendra was sleeping the other family members would try to calm and quieten the grandchildren so Pak Hendra could have a better rest.

4.3.8.6 Emotional expression and family response strategies

Expressing their emotions was not evident in this family; a conclusion based upon Bu Maya complaining that her husband never shared his problems with the family. Wina and Gama also mentioned that their father “is very quiet”, and never complained. However, it should also be noted that Pak Hendra actually has a centuries-old strategy to release his stress, that of meditation. By this ancient method he would release all his problems as he searched for inner peace and calm.

4.3.9 Hadi’s family

4.3.9.1 Family composition

Pak Hadi’s family includes Pak Hadi and his wife Bu Tari; both of them have hypertension. They have a son and a daughter, but these two do not live in the same house. Below is the genogram of Pak Hadi’s family (see Figure 20).

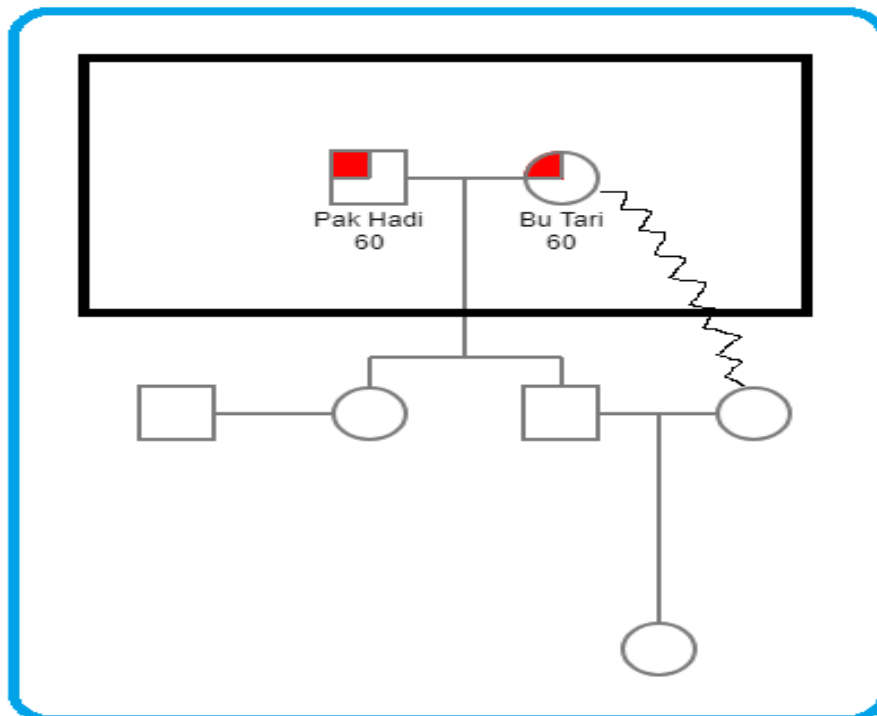


Figure 20: Hadi's family genogram

4.3.9.2 Developmental stage

This family was at the maintenance stage of their hypertension. This couple regularly attend the clinic's hypertension related weekly activities, taking their medication and exercising. They kept taking their medication because they worried they would suffer a stroke if they stopped doing so. They have taken their medication regularly since they were identified for hypertension.

4.3.9.3 Environmental data

The *Puskesmas* and park are within walking distance from where they live; thus for accessing exercise and healthcare services there are no issues. However, similar to Pak Sadu, food sellers were easily found in their neighbourhood. Bu Tari admitted that it is very convenient for her, because she does not need to cook every day, or spend a lot of time in the kitchen. She also mentioned her husband never

complained about his diet and menu; in fact he even has favourite meals he gets from the food sellers, and asks Bu Tari to buy those meals for him. The ecomap in Figure 21 depicts the family's relationship with their environment.

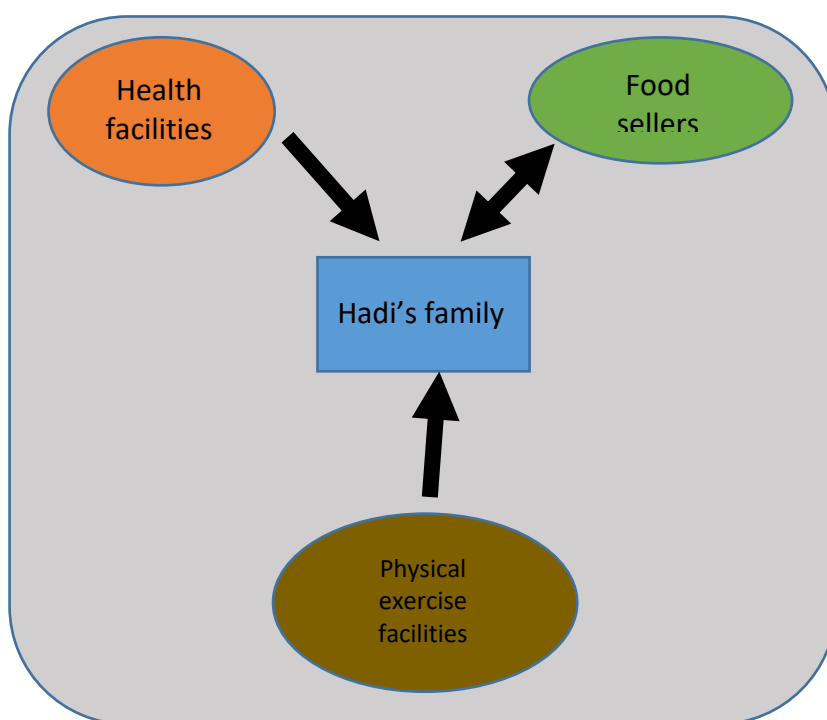


Figure 21: Hadi's family ecomap

4.3.9.4 Family structure

The couple were both identified with hypertension, but they believe they had managed to control their blood pressure. Both Pak Hadi and Bu Tari have the freedom to choose their activities to control their blood pressure levels. For example, both joined another physical activity programme beside the one in their *Puskesmas*; Pak Hadi joined the 'gate ball' group, while his wife regularly attends a yoga class. However, sometimes Bu Tari has to compromise her rest and sleep because of her role and responsibilities as a wife; someone who, in the Balinese cultural context, is both required and obliged to attend religious ceremonies. She blamed her poor

relationship with the daughter in law for still having to deal with the demands of these occasions. Bu Tari felt she should have retired from those kind of activities, to be replaced by the daughter in law, but she regretted that shift in roles had not happened, and in the present circumstances appeared unlikely to.

4.3.9.5 Family functions

Both participants understood their conditions, and they sometimes reminded each other about taking their medication. They also supported each other in doing the household chores. Bu Tari asked her husband to help her, so she would not feel too tired. As a good partner, Pak Hadi realised that his wife has to do many things, thus he agreed to share the chores.

4.3.9.6 Emotional expression and family response strategies

Strategies that this family used to tackle causes of stress include a) sharing the issues with their children and b) joining spiritual activities such as visiting temples in other parts of Bali. Bu Tari usually shares her problems with her children. However, sometimes she was challenged by the daughter in law, who limited her husband's contact with his mother. Bu Tari sometimes became frustrated because of her daughter in law's behaviour. The husband was more into spiritual activities, so he dealt with his stress by joining his colleagues on temple visits.

4.3.10 Kanda's family

4.3.10.1 Family composition

This family consists of Pak Kanda, Bu Dinda, Jepun (Pak Kanda's daughter), Jati (Jepun's husband), and the four children of Jepun and Jati; totalling eight members in all. The genogram below illustrates the family members' relationships (see Figure 22.).

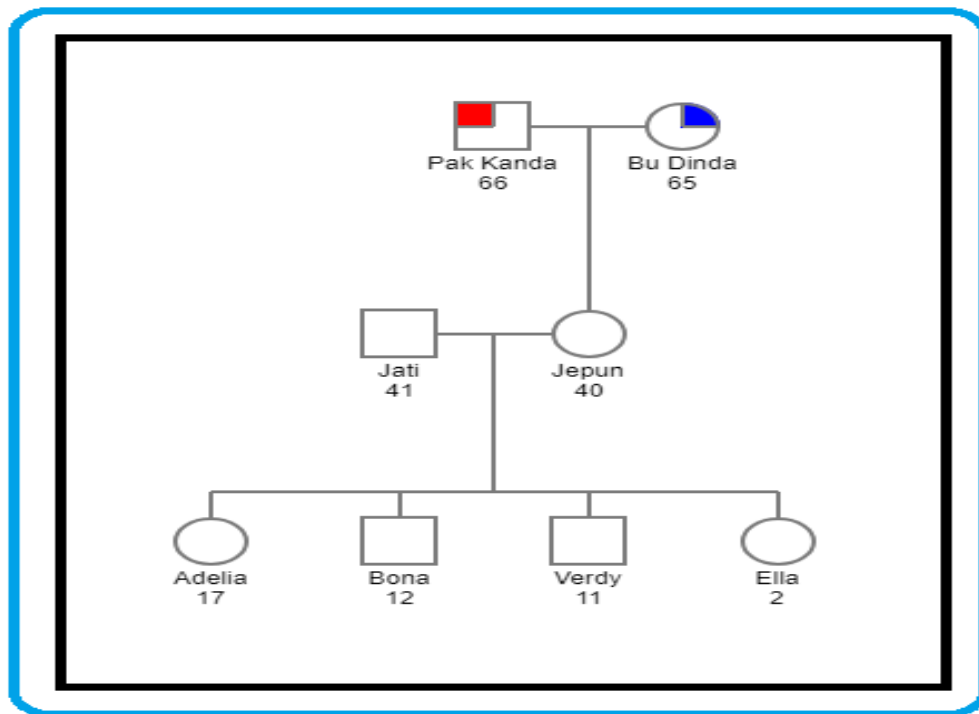


Figure 22: Kanda's family genogram

4.3.10.2 Developmental stage

This family is at the stage of taking their medication when necessary. Pak Kanda only takes his when he feels symptoms coming on, such as a headache. This reported behaviour was supported by his daughter and wife. A lack of knowledge about hypertension caused their rather sceptical and laissez-faire attitudes towards the taking of their medication. The daughter even suggested her father to not taking too much medication, and sometimes threw the medication away so her father will not take it. Such mind-sets will constitute a significant challenge for this family when it comes to them trying to properly control their hypertension.

4.3.10.3 Environmental data

The physical environment of this family may not cause any significant issues for the family in controlling their hypertension. This family's residence is very close to the *Puskesmas*, thus Pak Kanda can easily go to attend the weekly activities.

Their neighbourhood is also safe enough for exercise; Pak Kanda usually walks with his granddaughter around their neighbourhood. The playing times with his granddaughter are, for him, also his exercise times. However, his social environment may cause problems for Pak Kanda. When he told his colleagues he sometimes suffered from headaches they suggested he should start smoking cigarettes again, at that time he had actually quit smoking, to bring some relief. The family never complained about what his friends suggested to him, even though they acknowledged cigarette smoking was generally acknowledged to be extremely harmful to one's health if, at least in Indonesia, not also to one's wealth. The following ecomap in Figure 23 shows their relationship with the environment.

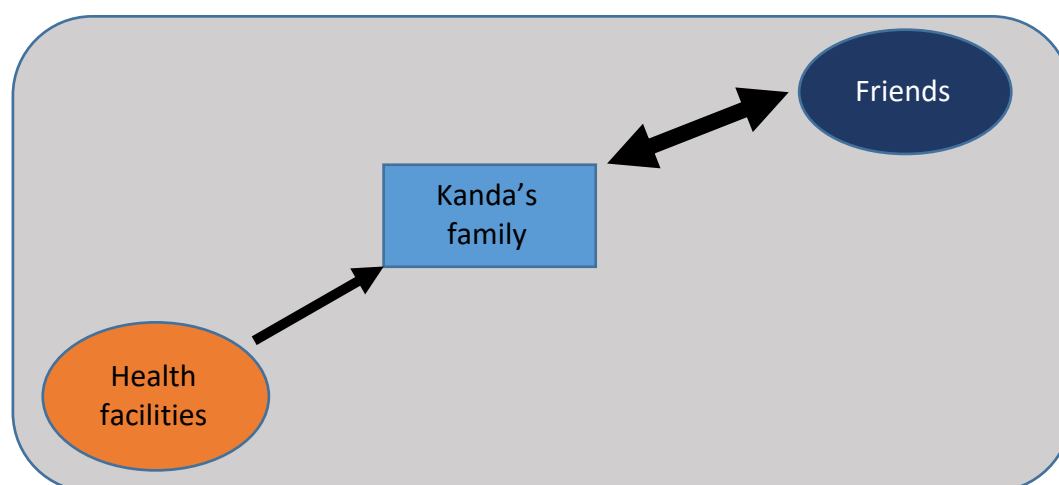


Figure 23: Kanda's family ecomap

4.3.10.4 Family structure

Pak Kanda's hypertension control tended to be influenced by the family members and his peers. He was still smoking, even though he knew it would almost certainly have a negative impact on his health. It is somewhat difficult to believe that the so-called friend, who suggested Pak Kanda should smoke cigarettes again as a cure for headache, is a physician. Pak Kanda believed him. His lack of knowledge

about medication was also a strong influence underpinning his poor medication routines; decisions that were supported by the other family members.

4.3.10.5 Family functions

The family understood that stroke can be the consequence of untreated hypertension, but they adopted a denial perspective by avoiding thinking about the possibility, instead believing their father will be fine. The family did not offer or provide any special treatment for Pak Kanda, instead they chose to normalise his condition. However, support would be readily available if he began showing any symptoms; help that mainly related to transport issues. This was mentioned by the son in law, who told me that the only support he could offer was taking his father in law to see the physician when he felt unwell.

4.3.10.6 Emotional expression and family response strategies

The family members were usually the first support sources available for each other, when they had problems. The other social network that was also important for this family involved their neighbours, who helped when the family needed it. Pak Kanda and his neighbours will have gathering in a pos sharing foods, chat and laugh together. This family enjoys close relationships with the neighbours, and they usually discuss about health because one of the neighbours is a physician.

4.3.11 Dago's family

4.3.11.1 Family composition

The family consists of six family members; however, I was only able to meet five of the six during my visits. Family members that I met were Pak Dago, Bu Siwi, Jenar and Jenar's children (a daughter and a son). Pak Dago and Bu Siwi have one daughter (Jenar) and she is married to a physician, they have two children. The

genogram below (see Figure 24.) depicts the relationship among the family members.

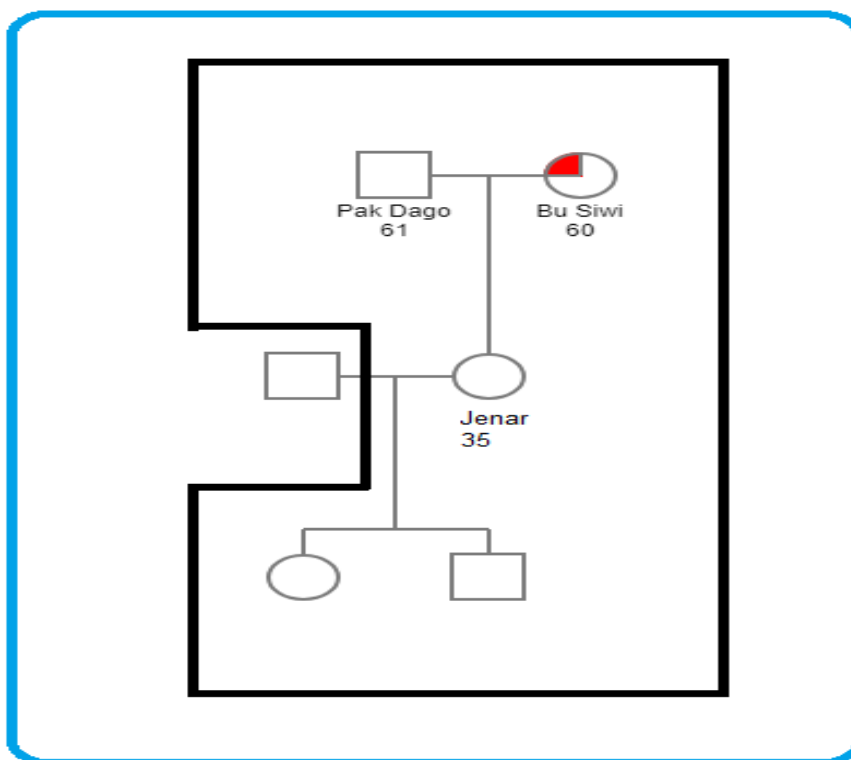


Figure 24: Dago's family genogram

4.3.11.2 Developmental stage

This family has reached the stage where they need to maintain what they have already achieved in hypertension control. Bu Siwi is taking the medication regularly; she has also joined the clinic-based weekly activities as well as practicing meditation at home. However, the challenge for this family is the social obligations that Bu Siwi has to deal with, which sometimes interfere with her rest and sleep habits, as well as the weekly activities at *Puskesmas*.

4.3.11.3 Environmental data

The physical environment may not create any significant or stress-causing issues for this family. They live very close to the *Puskesmas*, so Bu Siwi does not have a problem in reaching the health services and the weekly exercise sessions.

The *Puskesmas* also has a good programme for the control of chronic conditions, including hypertension. They live in a very comfortable house, and they have spaces for doing yoga at home. However, the social environment, especially the relationships within this family with their larger kinship circle, the society in their neighbourhood, as well as the traditions, have badly influenced Bu Siwi's efforts at controlling her blood pressure. Her husband is aware of her condition and all her challenges, but he has just accepted her situation and leaves Bu Siwi to negotiate her weekly activities at the clinic. The ecomap below (see Figure 25) shows the relationships between this family and their environment.

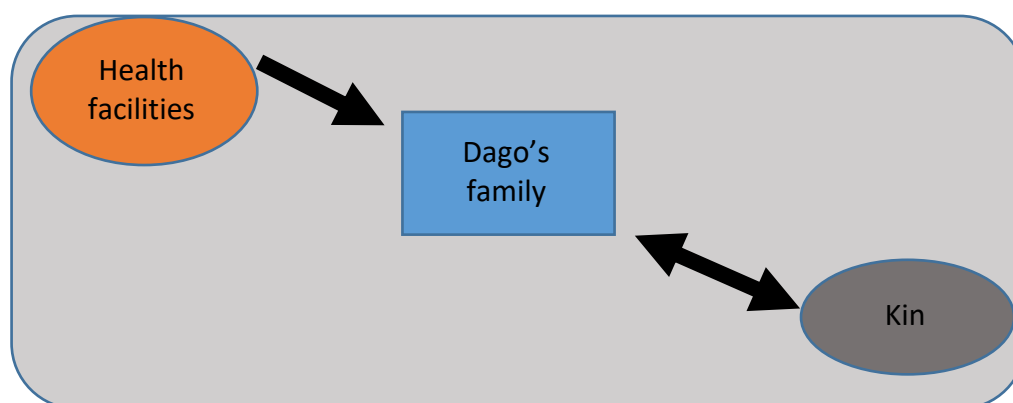


Figure 25: Dago's family ecomap

4.3.11.4 Family structure

Bu Siwi's roles and responsibilities as a wife and a member of society are a strong factor influencing her hypertension control. She sometimes misses the weekly activities because she has to attend certain social or religious ceremonies. The ceremonies in Bali can last for days, and sometimes Bu Siwi feels exhausted because of that; as a consequence of all the efforts she has been required to make she often feels her blood pressure has increased.

4.3.11.5 Family functions

Pak Dago always supports his wife in controlling her hypertension. He took Bu Siwi to *Puskesmas* and taught her medication. For the diets, Bu Siwi has control over their diets; mainly she makes meals that are safe for her and the grandchildren. When her husband wants tastier foods, he would buy meals from the food sellers instead of asked his wife to cook for him. All the family members have been very supportive of Bu Siwi, particularly relating to her efforts at managing her hypertension. The son in law is a physician, and has offered suggestions to Bu Siwi related to her medication.

4.3.11.6 Emotional expression and family response strategies

Bu Siwi usually uses meditation to reduce her stress. She said meditation was very helpful for her in terms of managing stress and calming herself down. Meanwhile the husband would use avoidance strategies to soothe her anger, by giving her space, and avoiding conflict.

4.4 Summary

I conclude there is evidence for two significant family issues relating to the control of hypertension. The first relates to family as the influence that reinforces and/or inhibits hypertension control. The family described constraints in hypertension control as coming from the roles and responsibilities of the patients in the family. As grandparents, the responsibilities involved in taking care of their grandchildren emerged as the factor that induced significant stress for the patients; that source of stress was believed to increase the patients' blood pressure. The roles and responsibilities of those same hypertension sufferers, as society members, have affected both their sleep and rest patterns. In addition, the families revealed that their financial conditions had strongly and negatively affected the patients' blood pressure, often causing it to increase, and sometimes leading to

emergency situations. The outcome of limited financial resources was that their diets were negatively affected, as there were insufficient funds to buy good quality food stuff. Also, because some of the participant- patients still had to work to earn money, that obligation interfered with, or affected, their sleep patterns. Family issues have been described as the source of stress for the patients, and the families believed that conflict arising from these issues badly influenced the patients' blood pressures. On the other hand, the family was also the first source of support available for the patients when they had to deal with such issues.

The second issue related to hypertension control was the characteristic of hypertension as an asymptomatic condition. Because of this unique and somewhat confusing characteristic families would support control attempts when they noticed symptoms of hypertension in the patients. Meanwhile, when the patients had no overt symptoms, the family just normalised the condition, perhaps based on the convenient principle: "out of sight, out of mind".

Further explanations about the two issues emerging from hypertension control, supported by interview and observation results, are discussed as themes in the following chapter.

5 Findings

5.1 Introduction

In this chapter I present the research findings as well as an analytical discussion of this study. The study aim, as set out in chapter 3 (methodology), was consolidated during the analysis process. Specifically, the research enquiry was focused on exploring families' experiences of daily hypertension control for one or more members in Denpasar, Bali, Indonesia. Building from this research objective, the following research questions were developed:

1. In what ways do family members experience the impact of an individual living with hypertension within a family group?
2. How do family members experience the management of an individual's hypertension control within the family group?
3. What are the potential facilitators for, and barriers to hypertension management in families?

In the process of analysis, an overarching theme of this study is 'family as a dynamic system in mediating the control of hypertension'. Through the analytic process, the lenses of general system theory (GST) by von Bertalanffy (1973) and von Bertalanffy et al. (2015), cybernetic theory (Wiener, 1950. 2013), the agency concepts (Giddens, 1986), and protection motivation theory (PMT) by Rogers (1975, 1983), were used to aid the analytical and theorising processes. In chapter 6 (discussion), the interpretations of the study's findings were also grounded in these theoretical constructs. The research findings presented in this chapter address the three research questions set out above.

This chapter is divided into five sections. Section 1) presents a conceptual framework to portray the aspects mediating hypertension control that are embedded

in the system principles which create the dynamics of hypertension control within family settings in Denpasar. Building on the overarching theme and the conceptual framework, the following sections discuss the elements that mediate the dynamic(s) of hypertension control within family setting in Denpasar: 1) roles and responsibilities, 2) economics, 3) stress and coping responses, and 4) presence and absence of hypertensive symptoms.

5.2 The conceptual framework of family as a dynamic system in hypertension control

System theory allows us to see how individuals influence each other in a family. The relationships are both interdependent and complex; when one part of the system experiences an event it will affect the other parts. The complexity of the members' relationships creates the dynamic of 'family as a system' in daily hypertension control within the Indonesian context. The feedback loop diagram below portrays the family as a dynamic system in controlling hypertension. The diagram is useful to portray the dynamics of system thinking; its main features include the relationships of variables, together with the variation and circular nature of the balancing and reinforcing processes (Mella, 2012). In a feedback loop diagram variables are connected by arrows to portray the causal influences among the variables (Sterman, 2001). The effects of causal connections are presented as polarities, either positive (+) or negative (-) on each arrow. The polarities represent how the effect, at the arrow's point, changes when the cause, at the arrow's tail, changes (Schaffernicht, 2010, Browne, 2017, Mella, 2012). The positive polarity represents the connected variables that changed in the same direction; if the strength of the cause increases the impact also increases (Mella, 2012); negative polarity means the connected variables change in the opposite direction. The feedback loop is an important feature in a system.

This feature occurs when the effect of a change propagates around the variables in a system through cause-effect chains and evokes a response which, in a feedback loop diagram, is presented as reinforcing or opposing the original perturbation (Laurenti et al., 2016). The reinforcing loop (symbolised with R) is a system in growth or an escalating effect because of equivalent influences between variables (Haraldsson, 2004). The opposing loop, also known as the balancing loop, (symbolised with B) indicates if there are variables that prevent the growth of the loop or there are variations in

influences between variables (Haraldsson, 2004). Figure 26 (below) portrays the findings of this study.

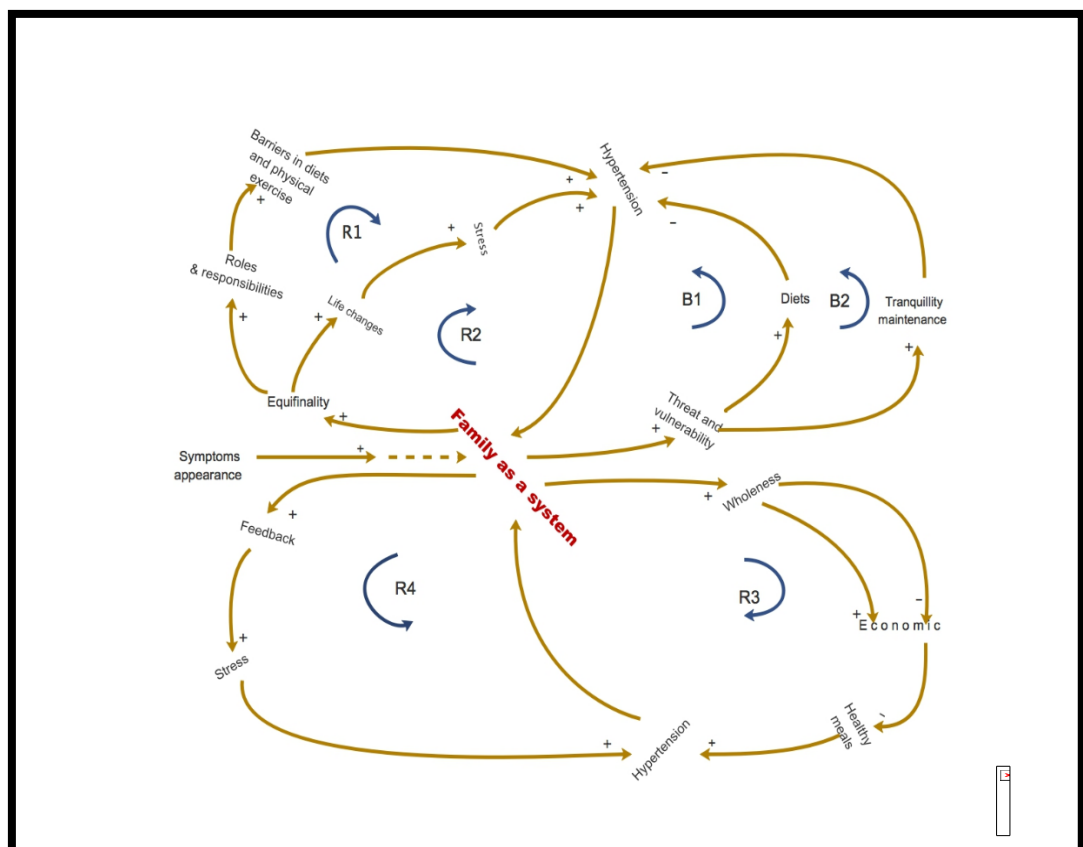


Figure 26: The complexity of hypertension control in a family setting

Family is a very complex system. Therefore, in order to understand the daily hypertension control of individuals, it is important to also have an understanding of the various family processes occurring within a family. These processes are the consequences of interactions within a system that have strongly affected the adoption of hypertension control among the individual members of that system. The process of control was extremely dynamic, involving various fluctuations as the result of different family processes that prevent the individuals' agency exerting their freedom. However, it should also be noted that at some point the family processes are also the ones that provide support for the patients.

The above feedback loop diagram, which presents the dynamics of hypertension in family settings, highlights related variables with their positive-negative polarisations. The diagram was based on three main elements which were the focal points of the family as a system: 1) equifinality, 2) wholeness, and 3) feedback. The positive marks mean the two nodes change in the same direction; the negative marks mean the two nodes change in opposite directions. The R and B letters refer to reinforcing and/or balancing feedback. The dynamics of hypertension control are influenced by roles and responsibilities, economics, stress and the coping process, and the threat of vulnerability. Those aspects are embedded in the focal points of family as a system portrayed in the above diagram. For this study those three focal aspects of family as a system contribute to the literature of family involvement in hypertension control in Indonesia.

1. One of the principles of system theory, *equifinality*, is the ability of the system to make adjustments in order to achieve *stasis* - the steady state (Von Bertalanffy, 1973). Equifinality is the principle in a system related to goal achievement, there being various ways to achieve those goals. Families experience changes during their life spans, not only creating new conditions that they have to adapt to, but also new roles and responsibilities for their members (Friedman, 2003). As

Bavelas (1982) suggested, changes are detected by 'the system' and so it begins to counteract the changes and restore homeostasis. The ways families counteract change inevitably compromise hypertension control. This outcome is shown in figure 25, where reinforcing loops (R_1 and R_2) prevent hypertension control from being implemented, thereby potentially increasing the patient's blood pressure. The implementation of hypertension control was prevented because: a) it was abandoned, or b) it was compromised. Further explanation of this aspect is elaborated in section 5.3 (see page 218).

2. The process within a family is the result of interaction between: i) the members, ii) members and external elements including: a) people, b) facilities, c) environment, d) global, e) regional and f) local dynamics (Cross and Barnes, 2014, Hammer, 1998, Carter and McGoldrick, 1989). The *wholeness* should consider all elements that are interrelated within a family, and this includes finance and economics (William, 1993). Economics and finance are important aspects in daily life, when both shortage and/or excess can influence the patients and their family in controlling hypertension; especially relating to meal preparation and the patient's sleep and rest patterns. Financial poverty has necessitated families to choose cheap foods that do not meet the dietary requirements of hypertension control. It was not only families experiencing financial hardship that affected food choices. It was noted that even when adequate funding was able to give more freedom in choosing ingredients for meals, several patients ended up buying unhealthy foodstuffs or actual meals that were rich in salt and fat. The 'wholeness' element, specifically the economic variable, resulted in poor diet choices; thus creating a reinforcing loop (R_3) that potentially compromises appropriate hypertension control. Further explanations of this aspect are discussed in section 5.4 (see page 244).

3. *Feedback* is a central concept of communication and control in a system (von Bertalanffy, 1973, Wiener, 1965). von Bertalanffy (1973) used the cybernetic theory by Wiener (1950) Wiener (1965) to explain how through the feedback of information: i) a desired value is maintained or ii) a target is reached (von Bertalanffy, 1973). Feedback provides the mechanism and information for goal seeking and the self-controlling of behaviour (von Bertalanffy, 1973, p.90). The cybernetics model explains the exchanging and transferring of information as it occurs in an open system (Wiener, 1965). Family as a system has members whose characteristics are interrelated, interdependent and which mutually influence each other (Walsh, 2015, Whitchurch, 1993). When one family member, a subsystem, or the overall system experience changes, then those changes reverberate across the family system (Whitchurch, 1993). Those changes challenge family life and create stress if the family and its members possess insufficient resilience to navigate through and recover from those challenges (Henry et al., 2015). The dynamics of hypertension control in the family context have been mediated by the stress and coping taking place in the family. The stressors come from the conflicts experienced by the family members, with lifespan-related role changes strongly influencing the patients' hypertension control performances. Furthermore, stress management was never considered to be relevant to hypertension management (Bokhour et al., 2012, Cornwell and Waite, 2012). However, in my research stress was perceived as a very important aspect in family life, particularly with its potential to increase a hypertensive patient's blood pressure (see reinforcing loop R₄). Further explanation of this aspect is discussed in section 5.5 (see page 256).

The control of hypertension in the family context is also strongly influenced by the presence and/or absence of any disease symptoms. In relation to the feedback principle, the presence of symptoms encourages the other, non-patient family

members to be involved in hypertension control. The balancing loops (B_1 and B_2) within the system show that the family members were more likely to be motivated to protect the patient when he or she reported that their blood pressure had increased, or the family members perceived the patient was becoming grumpy. When those symptoms appeared the family members started to feel the threat of an event such as a stroke could be experienced by the patient if no action was taken to help them. Therefore the family members would act to ensure the patient's wellbeing; particularly preventing blood pressure increase. Family's concerns toward hypertension symptom are in line with the principles of protection motivation theory: 1) the threat is severe, 2) the individual personally feels they are vulnerable to the threat, 3) if the coping response is effective enough to tackle the threat, and 4) the individual is able to perform the coping response (Plotnikoff and Higginbotham, 1998, Plotnikoff et al., 2010, Plotnikoff et al., 2009, Rogers, 1975, Ali Morowatisharifabad et al., 2018, Bassett and Prapavessis, 2011, Beirens et al., 2008, Bui et al., 2013, Flynn et al., 1995). Further elaboration of this aspect is discussed in section 5.6 (see page 286).

5.2.1 Summary

The balancing and reinforcing processes shown in figure 25 above, demonstrates the dynamics of hypertension control. The system properties shown in the diagram challenged hypertension control, although at some point(s) the family as a system supported the patients. In an individual context, self efficacy is strongly related to the intention to engage in healthy behaviour; however, as part of the system the individual's intention may be not executed. This 'failure' may well be due to the lack of supportive intentions from the other family members, resulting in an undesirable ambiance in which to perform hypertension control. Take, for example, the issue healthy diets: when the patient attempts to keep to their recommended

hypertension diet, the other family members may or may not comply as others' wishes take priority, especially those of grandchildren. The strength or intensity of an intention to provide support cannot be clearly or effectively predicted; a conclusion confirming the very dynamic processes involved in hypertension control. The dynamic process in hypertension control is a result of the family seeking a steady state. In seeking a steady state condition it is very important for family members to maintain the integrity of the system as a whole. This goal is commonly achieved by adapting the demands of individuals and subsystems, while also maintaining the individuals' and subsystems' integrity by letting them enjoy their status of autonomy within the system (Minuchin, 1974).

The dynamic of hypertension control in the family setting shows individuals' power and freedom affecting one another; consequently, the exertion of individuals' power and freedom acts as both constraint and support for the patients. Individuals' ability in self-governance gives them the power, as the agency with more freedom, to fulfil their needs and to have the authority to limit others' freedom. The above diagram explains that the interconnectedness, interrelation and interdependence of family members can be sufficiently rigid to affect the patients' agency. This somewhat contradictory scenario is because the individuals are the changers who generate the rigid and flexible structure of the family (Goldspink and Kay, 2007, 2004).

The following sections elaborate in detail the aspects that mediated the dynamics of hypertension control within family settings in Denpasar. Please refer to appendix 3 (page 397) for symbols used in interview quotations.

5.3 Roles and responsibilities

Roles can be defined as *"relatively homogenous sets of behaviours that are normatively defined and expected of an occupant of a given social position"* (Friedman et al., 2003, p.322).

In the family, a member can have multiple roles. For example a man can be: 1) a father for his children, 2) a son for his parents, 3) a husband for his wife and 4) an uncle for his nieces and nephews (Benokraitis, 1993, Howe, 2012, Bomar, 2004). Friedman (2003) calls those roles *formal* or *explicit*; such roles are strongly influenced by the demands and necessities placed upon the family by the larger social structure of the community. Not only does their position give a family member a certain role, but also their gender is a powerful decider. Traditionally, a women's role in a family is that of a caregiver, whereas a male performs tasks that are assertive and behaviour controlling (Bomar, 2004, Wright and Leahey, 2013, Friedman et al., 2003). However, today gender-based roles have become less evident or rigid due to educational improvements, changes in the labour markets, and modernisation globally (Attanapola, 2004, Carter et al., 2009, Moen et al., 1997). In modern Indonesia, gender-based roles have also slightly changed but that change has not, as yet, reached the state of equality between male and female roles in the family. Instead women have ended up with more roles; not only do they still have their traditional roles in the family, but now many are also full or part-time family breadwinners (Malhotra, 1991, Kopp, 2011, Utomo, 2016b).

The roles 'attached' to someone come with responsibilities, or a set of tasks that the person with a certain role is expected to complete as a function of their role (Friedman et al., 2003). The fact that someone can hold a number of roles that can make significant demands upon that person could produce role stress; when the individual feels unable to fulfil the role then she/he experiences role strain (Bomar, 2004). Bomar (2004, p.118) also suggests "*the role stress-strain framework could give role-related problems, including: role ambiguity, role conflict, role incongruity, role overload, role underload, role overqualification, and role underqualification.*" Sometimes the individual's capacity to make free choices (agency) has influenced the decision which role should be prioritised; a decision that can have social consequences at the level of collectives (Goldspink and Kay, 2007). In hypertension control the roles and responsibilities of the agent, (individual as a family member), have both dynamically facilitated and constrained hypertension management. In examining the roles

and responsibilities of the agent or agents in mediating hypertension control, this study takes a family system perspective.

In general system theory informed by a cybernetic approach, a system is an interrelated unit with equifinality as its basic property; a system which has the capacity to change an initial process to result in a different outcome, thereby achieving a steady state. This basic principle, in the context of family, is translated as the interdependence of the members in response to external threats, and the mobilisation of resources to adapt to changing circumstances (Silverstein and Ruiz, 2006, White, 2015). The increasing numbers of cases of both parents being involved in the labour force, and the common intergenerational living arrangements in Indonesian society, have given the elderly yet another responsibility to deal with while they are ageing (Kreager and Schröder-Butterfill, 2008, Kreager and Schröder-Butterfill, 2010, Schröder-Butterfill and Kreager, 2005, Snopkowski and Sear, 2015). Today's grandparents, and not just in Indonesia, have a new role as child-minders, providing care for their young grandchildren while both of the younger parents choose or are obliged to leave the house to join the labour force (Snopkowski and Sear, 2015). The grandparents will always be the 'second line of defence' due to their availability to substitute for the parents who are unable to provide and fulfil their parental duties (Silverstein and Ruiz, 2006). This is the manifestation of roles and responsibilities of modern grandparents in the context of the family system.

The family system is a hierarchical structure composed of subsystems. However, it is also a subsystem for larger systems, such as a community; thus the individuals are also embedded in a larger system, such as their temple congregation or local community (Cox and Paley, 2003). The family's interactions internally, and with broader society, help them to develop congruent roles and responsibilities that are applied both within the family and the community (Marks et al., 2009, Bomar, 2004). For example, the gender role is a result of an individual's social interactions, which enable them to differentiate between male and female roles ; with women representing nurturing behaviour, while the men represent controlling behaviour (Bomar, 2004). Families, with their permeable boundaries, are embedded in a

community's collective life. Thus one of the prominent sources of influence on the family, from the external environment, is social organisations (Mancini and Bowen, 2013). The relationships between families and social organisations are basically reciprocal. The social organisations provide support for capacity building, and these social organisations are the result of cumulative competences from the families; in return the community provides desired support to families (Mancini and Bowen, 2013). Due to the complexity of relationships between the family and social organisations, the family members will also take on certain roles and responsibilities; obligations which will consequently influence the dynamics of the family system (Cantor, 1991, Aldrich and Cliff, 2003) .

The two main roles and responsibilities discussed in this section are: i) as a grandparent and ii) as a member of society. The grandparents' activities when taking care of the grandchildren were observed as the interplay between constraining and facilitating hypertension control. As a grandparent, they become patients responsible for taking care of their grandchildren while those children's parents at work. The childcare role involves activities and duties including: a) providing grandchildren with all the care they need, b) feeding them, c) playing with them, and d) taking them to school. On the one hand these obligations can cause stress, while on the other hand they also encouraged the grandparent-patients to become more active and do more exercise, as when on 'escort duty'. Other than as a grandparent, participants with hypertension are also part of society and therefore they, and other family members, have the responsibility to attend social and religious activities. It is such activities that have implications for the patients' hypertension control in daily life. Roles and responsibilities, as part of society, were a constraining structure in hypertension management. The following section discusses the parenting roles and responsibilities that influenced hypertension management.

5.3.1 Grand parenting role

There are 7 out of 12 patients co-resident with their adult children and their grandchildren. Two out of seven of those patients reported that the grandchildren have influenced the hypertension control, especially in the context of lifestyle modifications, the examples are presented in the following sections.. This section has discussed the grandparents' roles and responsibilities in the context of the family system as a manifestation of resource mobilisation when the system experienced threats from both external and internal environments.

In Indonesian society, taking care of the grandchildren in intergenerational families is very common, especially when both parents participate in the labour force (Koentjaraningrat, 1985, Hoang et al., 2012, Hobart, 2001, Keasberry, 2001). Instead of just receiving care, many grandparents are now having to provide care for their grandchildren, because of the increasing number of cases of both parents participating in the labour force (Dannefer, 2010, Noveria, 2015, Aassve et al., 2012, Arpino et al., 2014, Bass and Caro, 1996). Dannefer (2010) suggests grandparents will provide partial to full care for the grandchildren, depending on the situation.

The interpersonal connections resulting in interconnectedness, and interdependence among the family members, create a rigid arrangement that obliged the patients to take care of their grandchildren. The grandparents may feel pride that they able to rear their grandchildren, that they are still needed by the family, but most of the time the child rearing activity is burdensome for them (Noveria, 2015). In this current study I found that for some patients their responsibilities in providing care for the grandchildren, when it came to managing their own hypertensive condition, acted as a constraint. Interestingly, other grandparent child-minding patients suggested their extra role actually helped them to manage their condition. The constraints may arise when the grandchildren limit the capacity of the grandparent to take action on hypertension management; for example the grandparents were stressed as a result of taking care of the grandchildren. However, a counter perspective could

be that the grandparent-grandchildren relationships may facilitate hypertension management, when the grandchildren through their playing activities promote physical exercise for the grandparents.

5.3.1.1 Grandparenting limits hypertension control

The previous section discussed the grandparents' roles and responsibilities in the context of a family system as a manifestation of resource mobilisation when the system experienced threats from both external and internal environments.

For example, Pak Hendra's family is intergenerational unit. Pak Hendra, as a grandparent, provides care for his grandsons. The family suggested taking care of the grandsons has increased Pak Hendra's stress levels. During the interview, I asked about their experiences of daily hypertension management; Bu Maya (Pak Hendra's wife) said her husband became easily annoyed, which she perceived as a symptom of hypertension. The symptom appears because of stress which is caused by the grandsons:

"but lately since he had the grandsons, right Pak? Perhaps taking care the grandchildren is tiring, they are stubborn,...maybe that is what causes him to get angry quickly" (Bu Maya).

Her statement was later supported by Pak Hendra and their daughter: taking care of the grandsons potentially causes stress to Pak Hendra and consequently causes his blood pressure to increase. Taking care of the grandsons became a very important aspect of family interaction related to hypertension control for this family. The grandsons became important to hypertension control because there were no issues related to other risk factors such as diets or physical exercise. The family members mentioned that they use healthy foods, rarely cooking red meat (pork and beef), with their diets mainly consisting of tofu, soya bean cake and vegetables. Meanwhile for physical exercise, Pak Hendra practices simple stretching movements and breathing exercises, which are considered as physical exercise, every morning. Therefore for

Pak Hendra's family, stress from the grandsons is the main issue for Pak Hendra when it comes to controlling his blood pressure.

Interestingly, other grandparent child-minding patients suggested their extra role actually helped them to manage their condition. The constraints may arise when the grandchildren limit the capacity of the grandparent to take action on hypertension management; for example, when the grandparents were stressed as a result of taking care of the grandchildren. However, a counter perspective could be that the grandparent-grandchildren relationships may facilitate hypertension management, when the grandchildren through their playing activities promote physical exercise for the grandparents.

5.3.1.2 Grandparenting facilitates hypertension control

This section elaborates the idea that the role of a child-caring grandparent, can potentially support the individual to control his blood pressure. This subtheme uses data from Pak Kanda's family. Before further elaboration about the role of Pak Kanda as a grandparent, and in order to emphasise the activities involved in taking care of the grandchildren are a positive influence for Pak Kanda in controlling his blood pressure, I present the other family members' perceptions about hypertension medication.

During the observation I noted that social control from adult family members had constrained hypertension control; meanwhile activities with the grandchildren were counted as positive support for hypertension control. Pak Kanda was a patient that I met in a clinic during the weekly activities, and his wife (Bu Dinda) was also a patient identified with both diabetes and hypertension. He is the coordinator for the elderly group; his duty mainly involves: a) preparing the snacks consumed by the group after the session, b) ensuring the venue is ready for the exercise programme, and c) checking the numbers present. The weekly activity in this particular clinic had started about 3 months ago, and Pak Kanda was appointed by the PROLANIS programme leader to coordinate the group, because he has experiences of various activities in his neighbourhood. The members of this group have been given

information about diabetes and hypertension, the treatments for both diseases, information related to diets and healthier lifestyles in general, as well as the weekly gymnastic and yoga sessions they can attend.

Pak Kanda did not take much care over his condition, even though he was the group's coordinator, where the aim of the initiative was to control hypertension and diabetes. He rarely took his medication or bothered to check his blood pressure, and this poor practice was actually supported by the other adult family members. The following interview excerpt illustrates poor hypertension management by Pak Kanda, which seemed to be supported by his family:

"I don't take medications". (Bu Dinda: hypertension and diabetes)

"If she gets (medication) from the clinic then she takes it, if it has finished then she won't take it anymore". (Pak Kanda: hypertension)

Even though they have the medication it is only taken when either patient feels the need to do so; thus the medication is saved in case they need it, but will be thrown away when they don't:

"I just ignored it (the medication), never checked it" (Bu Dina)

"Sometimes she got medication and ignored it and in the end she threw it away, that's her. As for me, I regularly have the stock, one pack, just to be safe" (Pak Kanda)

"Even though you don't take it every day?" (AS)

"Yes, last time, it's been two weeks, I bought a pack, I just took one this morning. It because I felt headache last night, I felt pain, this morning I took it". (Pak Kanda)

"I see, but did you check your blood pressure?" (AS)

"Not my blood pressure, no, I only check when...well even though I check it, it just the same, I just leave it, just take the medication if it's up" (Pak Kanda)

The other family member, their daughter Jepun, agreed that her parents do not have to take medication every day, because of potential side effects:

"I said 'better to throw away some of your medication, don't take it all the time' so no dependency, right?" (Jepun)

In the above excerpts, it can be seen that medication was not the main strategy for Pak Kanda and his wife to manage their conditions. The other participants were much more likely to rely on medication to control their hypertension. The couple were not taking medication as

the main treatment because neither took their medications regularly or particularly seriously. It was only taken when they thought they needed to, and blood pressure checks were treated with the same, somewhat cavalier attitude. The reason for not taking the medication was because of its actual and potential side effects; whereas Pak Kanda's excuse for not checking blood pressure was that no matter the results of the measurement, they should have taken the medications anyway. They both knew that their medications should be taken every day, but this just didn't happen. Social control from Pak Kanda seemed nonexistent; he knew that his wife did not take her medication regularly but he never did anything about her potentially harmful behaviour. Equally, Bu Dinda never encouraged her husband to take his medication regularly. Jepun, their daughter, indicated a negative social control attitude over her father's hypertension management, when she said to her parents that they should not take medication every day, because it creates dependency. The grandchildren seemed unaware of their grandfather's condition; they did not offer any comments during the family interview, even though I asked their opinions related to their grandfather's health.

In the context of social control Lewis and Butterfield (2007, p.299) proposed a concept of health related social control that is defined as "*interpersonal interactions that involve influence, regulation, and constraint of health practices*". They suggest there are controls exerted by more powerful parties over less powerful others that may promote or impede health behaviour practices, especially between spouses. The tactics of control can be negative or positive, direct or indirect, and bilateral or unilateral (Lewis and Butterfield, 2007, p.301). Positive control occurs when someone gives positive reinforcement, using a logical explanation to encourage the adoption of healthier behaviour. Conversely, negative control exists when the party involved mostly uses negative expressions as a tactic for showing disapproval, with those verbal or non-verbal expressions resulting in negative emotions in the target, such as feeling guilty (Lewis and Butterfield, 2007; de Montigny et al., 2017). Negative control was shown by Jepun in the above excerpt. Another concept associated with social control over health related behaviour, that explains how the family members can negatively

influence hypertension control, is the concept of 'indirect control'. This type of control is achieved when the first party only provide hints, designed to convince the other party (the patient target in this case) to feel obliged to follow up and act upon the hints (Lewis and Butterfield, 2007; Tucker, 2002). Jepun showed indirect control when she said, in one of the conversations, that she *"usually throws away her father's medication so he would not take 'too much' medicine"*. The other concept that explains negative influence by adult family members is when social control is a unilateral model, in which only one party attempts to change a certain type of behaviour (Lewis and Butterfield, 2007). Within this particular family the adult members seemed to have little interest in giving attention to Pak Kanda's hypertension.

Even though the two patients were not taking the medication regularly, this family preferred to use the medication to manage symptoms when they appeared, rather than using it to prevent the adverse effects caused by hypertension. Indonesians can be very sceptical about modern medication, because of their belief that the chemical components of the medication may cause adverse impacts to their bodies, or other negative side-effects (Prabawani, 2017). Therefore, they will only opt for modern medicine if they experience severe symptoms that cannot be cured using traditional medicines (Prabawani, 2017, Stevensen, 1999) . In addition, it seemed the influences from other family members, in particular Pak Kanda's daughter and wife, prevented Pak Kanda from taking his medication regularly. There is the belief in Indonesia that women have better knowledge about health matters due to their traditional roles as carers (Karim, 1995, Björnberg, 2005, Bomar, 2004, Friedman et al., 2003, Leahey and Wright, 1987b). Therefore, when Jepun offers negative hints concerning the taking of medication, Pak Kanda might believe her remarks and be influenced by them .

Instead of taking medication regularly to control the hypertension, Pak Kanda said he preferred to do physical exercise, especially walking, to manage his hypertension:

"Erm, I think physical activity is better than continuously taking the medication. I am better walking, relaxing, walk here and there, take a nap if tired, I just walk, sometimes I

couldn't sleep, couldn't close my eyes, it's better to go for a walk, it's also for this, for exercise, rather than deliberately going to the park for exercise" (Pak Kanda)

The excerpt above has shown that physical activity was preferred to medications, but he was not fond of planned physical activity, such as going to a park for exercising. It is fair to conclude that he actually did not enjoy the weekly group at the clinic either, as he said during the interview:

"I actually don't really want to go for the weekly activity, it just because they appointed me as the coordinator, I'm too lazy for that. Sometimes I leave, pretending to look for something, so I don't need to do the exercises" (Pak Kanda)

Physical exercise has been widely studied as a way to reduce one's blood pressure, and it can be a legitimate single treatment for early hypertension. However, for more advanced forms of hypertension, the implementation of aerobic exercise should be combined with medication (Börjesson et al., 2016). So, Pak Kanda should have taken the medication every day in addition to doing his physical exercise. However, it is predictable that the low frequency of his exercise sessions would not meet the requirement for them to be effective in reducing his blood pressure (Lee et al., 2007, Moreau et al., 2001, Sohn et al., 2007, Dimeo et al., 2012, Higashi et al., 1999).

The physical exercises that were performed at the clinic theoretically should be repeated at home, but Pak Kanda and his wife never put that idea to the test. His lack of motivation demonstrated his failure in exerting self-control. A person's higher levels of self-control have been related to better health outcomes (Moffitt et al., 2011). Examples of desirable behaviour include: a) a lower body mass index for obesity due to healthier food choices (Keller et al., 2016, Koike et al., 2015), b) engaging in physical activities (Gillebaart and Adriaanse, 2017, Schöndube et al., 2017) and c) lowering the risk of a return-to-smoking lapse (Muraven, 2010). One suggestion is that exertion of self-control depends on a limited resource known as 'self-control strength' (Muraven and Baumeister, 2000). Every time a person engages in an activity that encourages or requires the exertion of self-control, then this

limited source depletes, hence resulting in poorer, ever-decreasing levels of self-control on the following performances that may also need the exertion of self-control (Muraven et al., 1998, Muraven and Baumeister, 2000, Muraven, 2010).

Pak Kanda's 'fairly unenthusiastic' attendance at the clinic's weekly activity is an example of exerting self-control, but he fails to make a similar degree of effort in taking medication. It is worth noting that even though he exerted self-control to attend the weekly exercise activity, his motivation to do the exercises is actually low; as he said sometimes he skipped the exercise because he didn't want to do them. When he did not have the motivation to do exercise, it was probably because he had already exerted some self-control in attending the activity because of his role as the coordinator. A similar scenario can be used to explain the spasmodic taking of medication too. Improving his self-control can be very challenging as his spouse was at a similar level of self-control as he was. The other adult family members seemed to exert more negative than positive control on Pak Kanda and Bu Dinda regarding the quality of their hypertension management. However, Pak Kanda's role as grandparent seemed to help him to do physical exercise; an outcome that is explained in the following section.

Pak Kanda and his wife (Bu Dinda) are both retired. Similar to Pak Hendra, they have taken on the responsibility of care for their grandchildren during the day; especially the youngest granddaughter, now aged 2 years old, who still needs caring for when her parents are at work. The other grandchildren are all grown up and they do not need fulltime care anymore from their grandparents.

On my first visit to their house, I saw Bu Dinda was sitting outside their house with her granddaughter. The little girl wanted to play outside, which is actually a street with many motorbikes and cars passing by, so Bu Dinda had to watch her closely to ensure her safety. They do not have a space or play area inside the house for the granddaughter, so the street is her playground. Bu Dinda would watch her by just sitting outside, because she could not walk fast as she complained her ankles were painful. When the granddaughter wanted to walk

around the neighbourhood, then Pak Kanda was the one who usually followed his granddaughter. During the interview Pak Kanda mentioned that walking around the neighbourhood following his granddaughter is a good form of physical exercise for him, and the other family members agreed with this perception. The following is an excerpt from the family interview consisting of Pak Kanda, Jepun (his daughter) and Bu Dinda:

"The good thing is she willing to walk, and later on she would say "piggyback please?" then (we) go home on piggyback". (Pak Kanda)

"Is it part of your exercise?" (AS)

"Yes, because of the walks, her walks" (Pak Kanda)

"She goes everywhere, piggyback" (Bu Dinda)

He assumed his activity with the granddaughter is an exercise because it involved a vigorous walk, after which he could feel his muscles had been stretched:

"The walk was vigorous, it's not a lazy walk" (Pak Kanda)

"Where do you go? Is it far?" (AS)

"Around here, (we) circle this (his pointing finger made invisible circle for his neighbourhood)" (Pak Kanda)

"Visiting our neighbours, (h) exploring (h)" (Jepun)

"She doesn't walk, she runs, that's why we also run, she runs fast. That's why the doctor said walk is good, but not lazy walk, it has to have (vigorous) movements, to train the muscles" (Pak Kanda)

Taking care of his granddaughter gave him an opportunity to do physical exercise, in addition to the weekly exercise on offer at the clinic. The granddaughter's request to go walking around their neighbourhood has helped him to be more active. This walking is a big plus when compared to his poorly managed hypertension control and his unmotivated input to the clinic's weekly physical exercise programme. Thus walking vigorously with his granddaughter may help him to improve his hypertension management and his overall health status. Physical exercise is part of basic treatment for hypertension that may reduce the blood pressure by 11/5 mmHg, especially by doing medium-to-high intensity aerobic activity regularly (Börjesson et al., 2016). While the adult family members tend to exhibit negative social control that potentially hinders both patients' hypertension management, the roles and

responsibilities as a grandparent has helped Pak Kanda to do some exercise that he believed has encouraged him to exercise regularly.

In Pak Kanda's family, the roles and responsibilities as a grandparent have supported and encouraged him to engage with some physical activities. The activities with his granddaughter have given him another option in conducting exercise, due to the fact that he lacks motivation when it comes to the weekly exercise in the clinic, even though he is the group's organiser. This situation is the opposite to what was experienced by Pak Hendra. Even though the ages and development of their grandchildren were similar, Pak Kanda seemed pleased to use his activities with his granddaughter to improve his health. This aspect of family relationships might exert a positive influence on hypertension control; however, the hierarchy in the family regarding information about medication was a potential negative influence on that same issue. The family members who thought they had better information than the clinic's healthcare professionals would influence Pak Kanda and might create negative attitudes towards his medication.

Other than the roles and responsibilities as grandparents, the participants also experienced their roles and responsibilities as members of Balinese society, which also influence their attempts at hypertension control in their daily lives. The following section discusses the roles and responsibilities of family members when, as society members, they attend religious and social activities.

5.3.2 Attending religious and social activities

Social interaction in Indonesia is collective, consensual and cooperative (Bowen, 1986). Indonesians have key terms that are very significant to describe their social interactions and obligations to the community. These words include: i) *koperasi* (cooperative: is the jointly owned enterprise, which constitutionally is the basis of the economy), ii) *musyawarah* (consensus: which is technically the basis for legislative decision making); and the most fundamental among others iii) *gotong*

royong (mutual assistance). Even though *gotong royong* is a Javanese expression, it has become a central element of Indonesian culture (Bowen, 1986). Meanwhile in Bali, every family is a member of one or more social organisations or social groups. Membership will bind them to the obligations of the organisation, with the most important being *gotong royong*. The organisations the family members are involved in are usually affiliated to, or informed by, religious concepts and ceremonies (Hobart, 2001). The participation in social organisations is mostly compulsory, and the one who registers as the member is the head of the family. The family is then obliged to participate in every activity of the organisation and to be involved in carrying out the routine rituals and obligations, as well as any collective work (Warren, 1993).

Religious and cultural activities have inadvertently influenced the process of hypertension management, especially for diets and rest activities. Participants admitted they usually control their diets at home. However, when they attended religious and cultural activities, such as wedding receptions, they could not avoid or resist the foods that contain meats, and which they thoroughly enjoyed! Meanwhile, the female participants expressed their concerns relating to the fatigue they experienced due to the continuous ritual obligations they must meet. The first section below discusses the way social events influence diets, and the second section discusses how the ritual obligations disrupt rest and sleep patterns.

5.3.2.1 Social events influence diets

The families reported their attendance or involvement in social gatherings had influenced their diets in relation to their hypertension control performance. As in other Balinese families, Pak Sadu's family is a member of several social groups that cause them to have roles and responsibilities for every event of the groups they are in; mainly customary rituals for religious celebrations. In every religious celebration Balinese will serve traditional foods, the

most famous one being *lawar*. *Lawar* is a Balinese dish mixture of steamed young jackfruit (sometimes substituted with green long beans, soft coconut husk, and young papaya), grated coconut, mincemeat (usually pork, sometimes chicken, duck, bees, blood, herbs, and spices). It is usually eaten with rice, soup, fried meat, *jukut meurab* (steamed vegetables mixed with coconut and spices) and *sambal* (fried onion, garlic, chilli, mixed with salt). Male participants are particularly fond of this dish. In his interview Pak Sadu said how he really liked *lawar*, and he found it irresistible when he attends wedding receptions, or other celebrations. The following excerpt is the interview with Pak Sadu and his wife, Bu Mami, when I asked how they manage the daily diets:

"Since he eats at home, well we manage it our self. We cook foods that we can eat. If we eat at the receptions, then we will eat the foods that are there" (Bu Mami)

The excerpt shows they compromised their strict home diets when attending a reception by eating whatever was served to them. But, Pak Sadu then corrected his wife's point about compromising diets, which was also quickly supported by his wife:

"But we'll see" (Pak Sadu)
"I only took a little for each food" (Bu Mami)

They then gave an example of the foods they take at the reception venue:

"When I was invited to Negare, there they have, what was the lawar name?" (Pak Sadu)
"Lawar klungah" (Bu Mami)
"That's so delicious, that's my focus, it didn't have any effect" (Pak Sadu)

This couple believed meat potentially increases their blood pressure, but they made an exception for *lawar klungah*. This type of *lawar*, in addition to soft coconut husk, also contains meat, but they kept eating it. Moreover, they even ignored the vegetables because they focus on meat alone:

"Does it contain meat?" (AS)
"Yes, it's just a type of lawar" (Bu Mami and Pak Sadu)
"I ate that" (Pak Sadu)
"It must be with satay. I didn't take the vegetable stir fry, I get bored" (Bu Mami)

(He nodded, agreed to what his wife said) "*I just ate that.*" (Pak Sadu)

The excerpts above illustrated that this family managed to prepare foods that they required to control their disease in their regular days, but they could not resist the foods made of meat when they attended social events, such as wedding receptions. Attending social events was their excuse to enjoy meaty foods, and they would deliberately avoid vegetables, because they always had vegetables at home. Even though they enjoyed the meaty foods, Pak Sadu was still thinking about his hypertension, and rationalised that the *lawar klungah* (authentic dish in Negara region, made of soft coconut husk) was still safe for him, because it did not give him any problems. Although he keeps his diet on track at home, the food available at the venue was only meat, so he eventually just enjoyed the food that was available at the event.

A Balinese wedding is carried out on the basis of the good day that is determined by the priest; thus there are usually several weddings on the same day. This also applies equally to religious ceremonies, so in one day a person may attend more than one religious ceremony. Preparations both for weddings and religious ceremonies will take several days. In the preparation periods feasts are also served, as an appreciation for the villagers' work in helping the host. Every celebration in Balinese society will provide food for all the guests on that special day. Leininger (1970), in her seminal work, suggests that food within a culture has been recognised as marks of both religious and creative expression, used as a way to maintain social networking and as a tool to show social status. This concept in general is also applicable to Balinese society. Food has a very significant role in every celebration and religious ceremony due to its functions as an offering to God and maintaining social ties. Pak Sadu and his wife sometimes have to attend several events in a row, having their meals at the venues and as a result, eating a lot of food containing pork. Pak Sadu admitted that sometimes the foods he had at the social events were likely to give him symptoms, but then

he rationalised that chicken and pork *lawar* would not have such a bad effect on him as the beef *lawar* might do:

"Once I ate, when I attended many social events I felt like it gets higher, oh I felt it's going higher it's high indeed because of the meat you ate yesterday, right?" Yes, after attending social events, but there wasn't beef there, there wasn't right? It was just pork, chicken." (Pak Sadu)

This couple believed they could not avoid unhealthy foods when they attended social events or religious ceremonies, but they argued the foods they chose would not have any harmful impact to them, or there might be just a small effect that would not do any damage. Pak Sadu rationalised beef would be more dangerous for his blood pressure than chicken and pork. Rationalisation is a form of defence mechanism that is used to avoid conflict with reality (Bone, 1975, Sandler, 1976). On the one hand Pak Sadu was concerned about his blood pressure but on the other, he could not resist the temptation of *lawar*. He should have chosen another food that contained less fat, but to do so could well have attracted unwanted attention from the people at the venue. For example, if he did not eat the *lawar klungah*, which is an authentic dish of the region, people may ask his reason not eating 'their' food. Knutsen et al. (2017) suggested individuals sometimes would still enjoy foods that they should not have eaten to avoid others' attention when they attend a social event. Their attending social events is a part of their social role, and it is related to local wisdom called *Tri Hita Karana* (three causes of happiness). This concept suggests that to achieve happiness humans need to maintain harmonious relationships with God, the natural environment and other human beings (Pitana, 2010). The importance of attending the social and religious events cited above is because humans need to maintain good relationships with other humans in order to achieve and maintain a peaceful life.

Another example of social events influencing hypertension control was observed with Pak Dony, who also admitted that social events can be a challenge for him in controlling his diet. He occasionally meets his friends, an event that would inevitably involve eating. During

his interview he admitted that sometimes he would choose foods such as chicken and fish over mutton or pork. But if he could not get a safer food, then he would just eat what was available at the venue. He told me of his experience while eating *sate/satay* with his close friends. They questioned him about why he only took a very small portion of satay. Satay is an Indonesian dish made of seasoned and grilled meat, usually, chicken, mutton or pork, served with peanut sauce. A portion of sate usually consists of 10-12 skewers. The following excerpt is his experience during the gathering:

"Eating can be difficult, we have to be selective, so when we eat...ee..especially the food that causes (hypertension), it should be cut, cut. When I ate with my friends, when I knew that I have hypertension, with friends I wouldn't feel ashamed, I asked for mutton satay, only two skewers. 'Why are you so thrifty?' his friend asked. 'Just to taste' he replied the friend. If I ate alone I would be ashamed to just order two skewers, but because I was with friends it's ok so I just had two." (Pak Dony)

Pak Dony had been exercising slight control over his diets, even during the social gatherings. He managed to negotiate the quantity of the satay, and he did not feel ashamed because of that. However, in another social religious gathering that I attended with him, I observed Pak Dony fully enjoyed the pork feast served at the event. I had the chance to attend an annual religious celebration called *Cing Bing*, or The Tomb-Sweeping Day celebration with Pak Dony and his daughter, Dina .

The *Cing Bing* itself is a traditional Chinese celebration when Chinese people visit their ancestors' graves, clean the tombs and pray for them. The family members would bring various foods which mainly consisted of pork, as they believe their ancestors would enjoy the foods they loved together with them. The family members also burned some joss paper (representing money) so their loved one can use it in the afterlife. After they prayed then the foods will be shared. There were various feasts prepared after the ceremony, mostly made of pork, such as fried pork, pig roast, pork satay, and meatballs made of pork, duck, chicken and vegetable with coconut milk. Pork has always been a staple meat among Chinese society (Lai et al., 2018, Keating, 2011) and certainly pork was the dominant meat I could see on the table. On that day, Pak Dony ate a big helping consisting of rice, vegetables, and various pork

dishes. Pak Dony was aware the foods he had were not hypertension-friendly, but they were the main menu for that day. Pigs were domesticated for the first time in China in 10,000 BC and since then pork has become the main source of fresh meat for the Chinese (Larson et al., 2010). As the cooking skills developed, humans later processed pork into various foods that became a cultural element of the Chinese, which has been passed across generations (Shatenstein and Ghadirian, 1998). Thus, pork at a Chinese feast is part of preserving their cultural legacy and identity, even though they have settled in many other countries, including Bali. As a part of their culture, therefore in every celebration pork is essential to be served to the guests. After the celebration we went back to Pak Dony's place, and in the car he said the fat he ate that day was enough for several days ahead. However, he reckoned all the meat he had that day would not increase his blood pressure, because he made calculations based on his experiences so far.

The illustration above has shown that, as the part of the larger system, the family system must be involved in various social organisations or groups. The feast during the celebration usually led the participants to compromise their diets. Food at feasts, served during social celebrations, usually contains high levels of proteins and fats, mainly from meats. When participants attend the gatherings several times in a row, because they are part of various social groups, it is very likely their hypertension control diets will be in pieces. The foods served as part of religious activities have also caused the patients to compromise their diets. It is only with social gatherings, such as having meals with friends, that hypertension patients tend to have more control to decide what food they can eat. The hierarchy in the family system, especially when the family is placed as a subsystem of a larger system, as in the above examples, can be an aspect of family life that influenced the dynamics of diet control. In daily life at home the patients and their family members probably have more control over what they eat. However, when the patients have to perform their role as a member of a larger system, they must attend various social gatherings which always involve enjoying the feasts. Consuming delicious meals may be thoroughly enjoyable but unfortunately such

meals are not necessarily healthy for the hypertensive patients who eat them. On the other hand, in other forms of social events, the patients will have more control over their foods.

5.3.2.2 Customary rituals influence both rest and physical activities

The majority of the participants, 8 of 11 families, were from the Balinese ethnic group, with Hinduism as their religion. Bali has been acknowledged as a place that has maintained its distinctive social and cultural identity in spite of modernisation trends (Jensen, 1992, Boon, 1974, Howe, 2001). The Balinese Hindu are also known as an ethnic group that regularly perform a multitude of ceremonies that occupy large portions of their time and effort, thereby creating a significant impact on their lives (Jensen, 1992). Both men and women take part in the ceremonies, with each gender having their own roles. However, in this study the female patients reported that they had been significantly negatively affected by the ceremonies; an observation supported by their family members. The families that reported the ritual obligations had influenced their rest and sleep patterns were those of Pak Hadi and Pak Dago.

The above sections have described the involvement of Balinese families in various social groups; memberships that require them to engage in a range of customary rituals. The following part of this chapter features two female participants who complained that their ritual obligations might influence their hypertension control in their daily lives in a harmful way. The two participants were Bu Tari and Bu Siwi. The first illustration is from Bu Tari's family.

Bu Tari is a retired midwife, age 68, who lives with her husband, Pak Hadi who is also 68 years old. Both of them were identified with hypertension. This family is originally from Tabanan, a regency in the central part of Bali. This family lives in Denpasar due to work, but they will return to their village in Tabanan for religious and cultural ceremonies, as well as every time their relatives have a celebration. I found meeting this family was the most difficult to arrange, as Bu Tari cancelled our meeting three times because she was at the village and fully involved either with ceremonies or helping her relatives. This hectic and demanding type

of life, full of ceremonies, was also reported by Bu Tari during her interview. She made the point that there were times when she was just too busy, overburdened by having to do all the preparing herself. She seemed slightly frustrated by her condition, because her daughter in law should have taken her role in all the ceremonies, but unfortunately this change over did not happen as she had hoped for. Due to their relationship having been hostile since the beginning, the daughter in law disregarded her responsibilities to the family, and offered Bu Tari no help. Even though she was frustrated with the situation, Bu Tari kept performing her roles in the house, covering the absence of her daughter in law.

She was so sad every time she realised that nobody will continue to fulfil the obligations of this family to their temples, as she was getting older and did not have enough energy to do all the activities, most of which required fairly hard physical work. Most of the time she felt too tired and thought her hectic life for the ceremonies had affected her health. When I finally meet her for the interview, she reported that she had been ill for almost a week, and was hospitalised because of diarrhoea. She assumed her immune system might decline, as she was extremely tired during the ceremonies and wondered if perhaps some of the foods had also caused health problems.

Bu Tari believed that the continuous demands of *ngayah* (the members of the temple produce the offerings together in the temple complex) and *metulungan* (providing mutual assistance among all members of the village in the human-life-circle ceremony, as a form of maintaining a relationship with other human being) had drained her energy and therefore caused her blood pressure to increase. She regretted her situation and felt jealous of her sisters in law who can enjoy their old days without worrying about *ngayah* and *matulungan* anymore.

"Because of tiredness as an example, eee...the tiredness is the cause...oo well perhaps as I said earlier, I said 'That's why our ancestors..ehmm...our life must be (like in) estafet', for example me when I just married got duties from my mother in law, and she was free, the other sister in laws shared their duties, meanwhile I am 68 (years old) doing it all alone, well I think it's duty, sometimes (I am) tired, just like the other day, we had ceremonies continuously" (Bu Tari)

Bu Tari accepted her situation but she seemed to blame herself for the situation she was experiencing.

"Well, that's what sometimes happened, but I channelled it by saying 'our ancestors were great' that's why we need estafette , but now we can't estafette, it's our fault for having too few children" (Bu Tari)

The excerpt also shows that she implicitly showed her expectation for an act of reciprocity from the son; it is evident from her saying 'estafette' or the relay race (a runner gives a stick to another runner who carries that stick/load to the finish line). Other than that she also shows her envy towards other people whose children were meeting their parents' expectations, but not in her case. She slightly regretted and blamed herself for not having enough children. In Balinese society, the sons as the successor in the family also inherit the properties; in return they are expected to take care of their parents. In intergenerational relationships, reciprocity is expected throughout life; the younger generations help the older ones and *vice versa* (Brubaker and Brubaker, 1999). However, it looked the son and her daughter in law had chosen to deliberately ignore their obligation to the parents. Meanwhile Bu Tari felt she could not ignore her roles and responsibilities as a wife that needed to serve the community and her religion; although sometimes those efforts caused her to experience health problems. In order to conserve her energy she sometimes asked her sister to assist her during the busy days at the temples. Other than that, she always measured her strength when performing the duties, so that when she felt tired she would take a break. It is an obligation for her to perform her social roles and religious duties if there is no one else to do so. Her husband, Pak Hadi, did not have other options either, because he also has his own role as a male family member, although his son sometimes took over the role. However, that transfer was only partial because the son has to go to work. Ignoring the obligations in religious ceremonies is something that Balinese would never do. To do so would mean they would breach the five principle beliefs of Hinduism which are known as the *Panca Sradha*. The principles are: i) believe in the existence of a Supreme God (*Brahman*), ii) believe in the

existence of the eternal soul (*atman*), iii) believe that every deed has reward (*karma*), iv) believe in reincarnation (*punarbawa*), and v) have the conviction that the ultimate purpose of life is unity with God (*moksa*). Primarily, ceremonies are held to thank God for the blessings of life and resources that have been given to the people. An important group of ceremonies, called *manusa yadnya*, mark each milestone of a human's circle of life, with the purpose of refining the wrong deeds in the past, so the present and future life would be better (Jensen, 1992). Family members also have the obligation to attend *manusa yadnya* ceremonies for their relatives on both the husband's and wife's sides. Thus ceremonies in Bali can be a huge burden for the Balinese, as they spend so much time, energy and resources dealing with their demands and roles that their lives are affected in many different ways, not all of which are good (Jensen, 1992).

The second illustration is from Bu Siwi's family. Similar to Bu Tari, Bu Siwi also has to continue fulfilling her roles in society, which she should have retired from, considering her age. However, the reason she was actively involved was slightly different from Bu Tari. In Bu Siwi's case, she was still dealing with her social responsibilities because this family do not have a successor that could continue the family's patrilineal line and perform the required obligations in religious and social life. Marriage is a must for Balinese Hindus, so that children can be born to continue the patrilineal line. In a Balinese marriage, when a woman marries a man, she will leave her family's house and join her husband's family. Balinese worship their ancestors in the family or clan temple, and a woman not only leaves their family but also her ancestors during the wedding ceremony, to join and worship her husband's ancestors. The newlyweds inherit all the social and religious obligations of the husband's parents. Therefore, even though Bu Siwi has a daughter she 'belongs' to her husband's family, and performs the required roles in that family. It is for this reason that Bu Siwi has to meet all her societal obligations by herself. Unlike Bu Tari, Bu Siwi was unclear when I asked her if religious ceremonies affected her blood pressure:

"Maybe I have the feelings, I just control it immediately, when I feel the symptoms, the headache" (Bu Siwi)

She hinted that perhaps the ceremonies she must attend caused her blood pressure to increase, but then mentioned it easily can be controlled. But her husband's statement gave a clearer view that the ceremonies potentially influenced her blood pressure, because most of the time she suddenly presented the symptoms in the middle of the ceremonies. He also emphasised that women take important roles in religious ceremonies. Hypertension can be a nuisance for the smooth running of those ceremonies, which continued without interruption even though she might feel ill during the process.

"Being sick certainly has an impact on us, and it is highly likely that we can't do our daily activity normally, especially when we have to attend the ceremonies. Being sick will prevent us from doing our house chores or daily activities smoothly especially when we have a traditional Balinese ceremony. It is the women in the family that plays the [most important] role for the ceremony, right? We, as men, can be categorised as the supporting factor only [in Balinese ceremonies]. If her blood pressure is not at the normal level, automatically she will not be able to do activities (the ceremonies) normally" (Pak Dago)

Pak Dago's interview excerpt implies his wife was in good shape but sometimes presents symptoms; thus she needs either to have a break or to continue with the ceremonies and negotiate her way around her unsatisfactory condition.

Not only have her social obligations compromised her sleep and rest patterns, but they have also interfered with the regular exercise sessions at the clinic. So far Bu Siwi has managed to control her blood pressure by taking medication and exercising regularly. However, but due to her roles that required her to attend the ceremonies, she sometimes has to cut back on her involvement in the weekly exercise activities at *Puskesmas*. Her husband thought that the Balinese traditional obligations had interfered with his wife's exercise activities:

*"I always attend and join it. Only last time I left earlier, I went to Kelandis, there was a ceremony (Bu Siwi)
(She) "only joined the exercise session" (Pak Dago)*

"That is the idea. We can say 'Please excuse me for leaving', 'I have another thing to do'". (Bu Siwi)

"That's the Balinese tradition, it is the most difficult to avoid" (Pak Dago)

In the above excerpts, Bu Siwi said she only attended the physical exercise, and left the health education session. Both husband and wife reaffirmed that their traditional obligations cannot be ignored, so Bu Siwi admitted she might at times have to skip the clinic's activities completely.

From the two illustrations above it can be seen that both families have adequate knowledge about their conditions and are aware they have to take care of themselves in order to prevent any harmful impact from hypertension. They have also become actively involved in hypertension control activities; however, their roles and responsibilities in both religious and social events have sometimes interfered with their practice in hypertension control. The demands from continuous involvement in ceremonies resulting in a lack of rest and sleep have triggered hypertensive symptoms. Those sometimes onerous demands also caused both women to sometimes be absent from the weekly exercise sessions at the clinic. But they could not avoid the ceremonies, as that would mean breaching the principles of Hinduism. The bond with their social network has become a rigid structure that at times negatively influences the hypertension control of these two ladies. Juggling with their weekly exercise and rest activities, as well as their sleep patterns, is a consequence of their involvement in various religious ceremonies. Meanwhile their participation in those ceremonies is the result of the family being a part of the larger system. Their failure to fulfil their familial cultural obligations would result in feelings of guilt to their society and God. Therefore, they would still continue fulfilling their roles and responsibilities.

Religion, whatever its cultural importance, can be viewed as a two-edged sword; it can be both a support for the family as well as doing harm (Dollahite et al., 2018, Inozu et al., 2012, Park, 2005, Thomas, 1995, Cojocar et al., 2011, Coetzer, 2010, Fincham and Beach, 2014). Religion is recognised as a support for the family because it may give meaning to a

family's life, ensure feeling of safety and organise people into communities that support their members both psychologically and materially (Dollahite et al., 2018, Park, 2005, Hood Jr et al., 2018, Stark, 2012, Brotherson and Soderquist, 2002). However, religion can also be harmful for the family when it gives members feelings of guilt, if they fail to perform the rituals and doctrines associated with their religion (Inozu et al., 2012). Gender inequity, as the result of practicing a particular religion, has also been recorded as a form of family damage religion caused by religion (Schnabel, 2016, Sigalow and Fox, 2014). The last two religious features cited above: a) guilt and b) gender inequity seem applicable to the situations of Bu Tari and Bu Siwi.

5.3.3 Summary

The properties in family systems have performed as a rigid relationship that can exert both negative and positive influences on hypertension control. However, the major part of the rigid relationship resulted in negative influences for the patients. The potential for self-adaptation as the basic premise of the family system has influenced hypertension control in both negative and positive ways. The self-adaptation has both prevented and supported the individual, as 'agency', to make the effort to control hypertension. The ability of the family to adjust in order to maintain a steady state, by performing roles and taking responsibilities such as caring for grandchildren, has impacted hypertension control. Some participants felt their roles as child-minding grandparents had, at times, increased their stress levels, whereas for others being a child-minding grandparent both encouraged and required them to be more active.

In addition, the family system's hierarchical character played an important role in influencing the dynamics of hypertension management. The hierarchy in this case refers to a scene when one of the family members was perceived as having better

knowledge than the patients about health, but actually their knowledge was unreliable. Despite that 'blip' the other family members seemed to believe 'the family expert' more than the information obtained from the healthcare provider. The hierarchical feature was also observed because family is the subsystem in the larger community, which results in obligations that the family members have to fulfil. Consequently the obligations they are obliged to meet affected their health and compromised the quality of their hypertension control.

5.4 Economics

The most fundamental aspect of a system is its wholeness. The system cannot be understood without understanding and embracing all the parts of that system. As a whole the family not only comprises of family members; there are other aspects of the family as well including the economic dimension that supports the family process. Finances are a significant aspect in a family system, as its function relates to exchange, production and consumption activities to achieve the desired ultimate purposes of the family (Williams, 1993). Socio-economic conditions are a powerful structural influence on a family's health behaviour. The socioeconomic hardships that I observed among the participants, the majority of whom had retired, significantly influenced the control of the patients' hypertension. This section elaborates the economic conditions that were seen to influence the patients' hypertension control and management. The issue of economic constraint emerges because participants still have to work and earn money; a requirement that affected both their rest and sleep activities. In addition, their lack of financial security obliged the affected participants to accept diets that were poor in both quality and quantity, which were all they could afford.

Most patients retired to then either live with, or without, a pension. Some of them experienced financial hardships, while others managed their finances to meet their daily

expenses. Financial conditions became a priority for all participants because they felt uncertain about their individual futures without the security of adequate financial resources. However, I was given the impression that asking for help from their children might raise uncomfortable feelings on both sides, as their children had their own families to feed. Finances are one of the barriers that have been studied widely to evaluate their impact on hypertension management (Borzecki et al., 2005, Bosworth et al., Dhaliwal et al., 2017, Hill et al., 1999, Hill and Sutton, 2000, Lister and Merritt, 2013, Siegel, 2005). In this study, it was generally those patients without pensions who struggled to meet their daily expenses, compared to their counterparts who had the security of their pension behind them. However, even some patients with pensions were still struggling with their financial situations, because the money was not enough to meet both their needs as well as those of their families. This corrosive deficit situation affects the quality of hypertension management, especially for the adoption and continuity of healthier behaviour. One possible exception to this difficulty is that accessing medication may not directly affect a family's financial condition, because patients can get their medicines free from the clinic. Even in the minority of cases, when they have to buy, the price is still affordable. The greatest negative effect of financial hardship on those with hypertension is reducing patients' access to healthy diets although other activities, such as sleep and rest patterns, were also problematic for some patients. The poorer patients have been forced to compromise regarding the quality of their diets, as well as their rest and sleep activities. The following field notes and interview excerpts illustrate how financial hardship influenced the control of hypertension management, and how far was the quality of that control from the ideal. The first part of the presentation discusses Pak Dony's family, followed by Pak Agung's where the control over diets was influenced by their financial condition. The second part discusses Pak Jono's sleep patterns, which were informed by his obligations to meet his and his family's financial outgoings.

5.4.1 Financial conditions influence diets

Their financial situations are significant influences for Pak Dony and Pak Agung when it comes to diet control. However, the economic status of these two participants resulted in slightly different impacts on those diets. During my observation with Pak Dony's family, on my first visit I noticed a big shelf that was almost empty, in a room that looked like an office, which was where he hosted me. There were some bottles covered with dust that looked as if they have been there, undisturbed, for ages. He told me that he used to sell health supplement products and that the room we were sitting in used to be his office, where he received his customers. He told me about his business and family on the first day I visited him. Pak Dony used to sell supplement products, and his business had started to grow; he even won some awards from the product company. Now the situation had clearly changed. He was still selling the products but could not earn as much as before; now the income was roughly £100 every month.

Other than selling the supplement products, his elder daughter, who lives in another city, helps him to meet the obligations associated with his teenage daughter Dina's education: paying her tuition fees, as well as meeting the cost of her books and stationery. The elder daughter herself was studying at that moment, so she could not fully help her father to meet his daily expenses. Pak Dony also had a son, but that was an estranged relationship and his son was not discussed. The interconnected nature of the family system has led the elder daughter to make the effort to keep the equilibrium in the family, by stepping forward to pay her younger sister's tuition fees. Meanwhile, Pak Dony could not, and probably did not, expect support from the son due to the conflict between them. The self-adaptive nature of the family system is evident in what the daughter did and was doing for her family. The possible explanation to describe what she has done for her family could be found in their Chinese roots. In a Chinese family, the daughters are expected to provide support before they marry,

meanwhile sons throughout their lives have formal obligations to provide support to their old-aged parents (Xie and Zhu, 2009). In Pak Dony's family, in the absence of the son, the elder daughter decided to help her family, but this might cause a concern for Pak Dony when she has to leave her natal family after she marries. Meanwhile for his son, the problem was the boundaries set by Pak Dony; he decided to shut down any communication with him. If they had enjoyed a better relationship the son might have taken part in supporting the family.

Pak Dony admitted that he could not provide himself a proper diet to control hypertension, because his family rarely cooked; they mostly bought meals from the food stalls to save money and time. I had the chance to follow him when he bought some breakfast from the nearby food stall. He said the stall is his kitchen every morning. The meal consisted of noodles and shredded chicken, which cost him Rp. 4000 (£0.23pence). That was very cheap and too little for two people; the foods he bought for breakfast were most of the time part of his lunch as well. The other observation I made was when I visited this family in the evening. I asked whether they had finished their dinner and the answer was "yes", the food they ate for dinner was the Chinese foods left-overs from their lunch. It seems that not only the quality of the foods they eat was compromised but also the quantity. The financial challenges Pak Dony faced had forced him to compromise on what he ate, although he was quite aware that he should have controlled both the quality and quantity of his food intake. This awareness was revealed during his interview:

"Ee on average my blood pressure is over 140 (mmHg), the cause I don't know. As in a book I read it is tolerated to 140 (mmHg), it is because of the age factor, food as well, because I don't cook my own foods, sometimes for the purpose of obtaining better taste, the sellers add food enhancer and that sort of thing, so the customers stick with them. For food I never thought about it, I never cooked it by myself, very rare". (Pak Dony)

"Do you mean that you cannot control your foods?" (AS)

"For the food enhancer is very difficult, because I buy foods, but I know the food sellers 'oh this one usually like this, and that one like that" (Pak Dony)

Pak Dony understood that he should have reduced his salt intake, and that he should choose food sellers that might cook healthier foods. However he rationalised that 'his' sellers were aware they must keep their customers, so they used salt and food taste enhancers, apparently to good effect in Pak Dony's case.

Healthier foods such as lean meats, vegetables and fruit are more expensive, thus the higher the income the better food choices people could have (Engler-Stringer, 2011, Drewnowski and Darmon, 2005, Darmon and Drewnowski, 2008, Monsivais and Drewnowski, 2009). Pak Dony expressed that he could not afford fruit every day, and just occasionally he bought fresh vegetables. He might choose a healthier diet when he earns more money; however, his financial challenge has prevented him from having more control over his daily diets. He was fully aware of this but there was not much he could do to change the situation. As a single parent he also struggled to meet his daily expenses by himself, especially when his earnings were much less than before. If he spent too much on food, then he would not have enough for to fulfil his other needs. As a system, one of the family members, his eldest daughter, adapted to the circumstances by providing support for the family. Another option was to compromise their needs, such as when Pak Dony reduced the quality of his diets. As a single parent, Pak Dony has to cover the household expenses; to achieve that goal other needs, such as diet, were compromised.

Another example of finances influencing food choices is illustrated by Pak Agung's family. The situation is dissimilar to what Pak Dony experienced with his financial situation. Pak Agung has a pension as he worked in logistics for the Indonesian army. Every month he receives the equivalent of around £150. During my interactions with this family, almost all the family members admitted that when Pak Agung received his pension most of the money would be spent on food. His

daughter in law, Rina, mentioned that the food he frequently bought when he had money in his pocket was meat, especially pork. She said she felt helpless at the beginning of each month, because that was when her father in law had the money, and she could not stop him from buying meaty foods. Her concern was expressed during the individual interview I had with her at her stall:

"Most of the time, when his pocket is full I say 'Pak, can you reduce the nasi be guling?' (a Balinese dish consists of rice and roasted pork, mixed pork and vegetables salad, fried innards of the pig, soup with pig fat) only for him to reply 'Well, when will I have the time to enjoy it, now is the only time I can enjoy it'. He would say that" (Rina)

Pak Agung spoiled himself with his favourite foods every time he received his pension, and his reason for doing this was because he thought he would not have much longer in his life to enjoy his favourite foods. I assumed this response to be the result of him finally being able to use his money for his own needs; all his children are grown up and have their own jobs and wages. So he no longer held the role as the primary provider for his children's needs, as when they were younger. Now he could spend more money on himself, especially for food. Extra income and diet improvement has been investigated by Du et al. (2004), who concluded that the extra income for poor people in developing countries would most likely be spent to improve their diets. However, the concept of improvement did not focus on health related issues; instead, it always meant the ability to buy foods containing extra edible oil, pork, or other meats. Pak Agung clearly only wanted to satisfy his desire for tasty foods. As Rina noted, after the first two weeks of every month all his money had gone; when the cash is gone Pak Agung will eat the home cooking that Rina prepares for the family. She usually cooks fish and soya bean cakes, which would rarely be touched by Pak Agung, when he has his pension money.

"I knew that Bapak only has the money at the beginning of the month, when it's finished he will eat my foods, I obviously cannot provide foods (he likes) every day, cannot afford it" (Rina)

At one of our meetings, she told me even though sometimes Pak Agung cooks for his family, the ingredients are mainly meat, especially pork. Rina understood the meaty meals that her father in law always buys contain lots of fat that would almost certainly increase his blood pressure. Meanwhile her home cooking contains less meat, which she believes is a healthier diet than the *nasi be guling* loved by her father in law, who only eats her meals when he has run out of money.

The illustration from Pak Agung's family has shown just how clearly financial conditions can influence diet decisions. When the money is available the individual has more freedom to choose the meals she/he likes, with more power to exert, and so that individual patient (in this case) becomes resistant to all the rules about foods. As Rina admitted, she could not stop Pak Agung from buying his favourite meals when he had money in his pocket. Meanwhile, when the money was gone, Pak Agung would eat Rina's meals without complaint, even though he did not like the food because it was mostly vegetables and fish.

The two families above might have shown signs of double burden malnutrition: obesity and under-nutrition. Indonesia is similar to the other developing countries is facing this problem. This modern condition reflects the changes of diets and leisure-time activities that in many countries have increased the prevalence of obesity. Meanwhile, at the same time, under-nutrition remains a big public health issue (Hanandita and Tampubolon, 2015, Winkvist et al., 2000, Doak et al., 2005, Oddo et al., 2012). Even though both Pak Dony and Pak Agung cannot be identified as clear examples of either over-nutrition or under-nutrition, the facts are: a) that Pak Dony has been obliged to compromise the quality and quantity of his foods due to

financial hardship, while b) Pak Agung enjoyed foods high in calories because he could afford it, at least for the first two weeks of every month.

5.4.2 Financial influences on sleep activity

Pak Jono used to work in a TV station with quite a high position before he retired; as a result he now receives around £170 per month. In addition to the pension he is still entitled to live in the house that is provided by the company. So, for his daily expenses his pension is just enough for him and his wife, Bu Karti, to live on. As for his daughter's family, both his daughter and son in law are self-employed, the daughter runs a small business producing soya milk, and the son in law runs a small business making shelves. The monthly bills are shared between Pak Jono and his daughter's family. Bu Karti, Pak Jono's wife who is a good cook, sometimes received orders for foods/meals, so she is another financial resource for the family. This couple are still eager to earn money in their old age because they do not want to burden their children if that can be avoided. As Bu Karti told me when I came to observe them while making the soya milk:

"I am happy can help her (Mila), I can earn money too. It's such a waste if she has to employ someone else, it's better to hire us. So I can have some savings, we don't want to burden others" (Bu Karti)

The whole family finally owns the small business, because they are all working in it and for it. It was Mila who initially came up with the idea, and she planned to hire other people to work for her, but her parents stepped forward and offered to help her run the business instead. All the adult family members help each other, for the business is all they have. Pak Jono and Bu Karti work hard for the soya milk production, being mainly involved in the making process, while Mila distributes the milk to a traditional market near their house, and to some small kiosks nearby. They produce the milk twice every day, at midnight and in the afternoon. The midnight

session starts at 01.30 hours (1.30 am). Pak Jono has to get up first and start grinding the soya beans using a hand-powered grinder, and gets the white liquid from the beans that later will become the milk. The next process is done by Bu Karti, she boils the liquid, adds the flavours, and packs the cool milk into small plastic bags and bottles. The last process will be done by Mila, who distributes all the ready-packed milk at 4am. The total time needed for each morning's production around 2.5-3.0 hours. The afternoon session takes a similar amount of time; they usually start at 13.00 hours (1pm) and the milk will be ready by 16.00 (4pm). Pak Jono has to get up around midnight and when he finishes his role, he will go back to sleep in order to and get up again at 07.00 (7am).

Pak Jono's sleep pattern, where he regularly wakes up at midnight, has triggered my concern over his hypertension because sleep itself, and the quality of that sleep, have a significant impact on the human haemodynamic. Night sleep deprivation has been linked to increased blood pressure, and is therefore harmful to the cardiovascular system (Choudhary et al., 2017, Lusardi et al., 1999, Pankow et al., 1997, Morris et al., 2013). Night sleep deprivation prolongs the rapid eye movement sleep phases, during which the heart rate reaches its highest level; a process that is effected by the activation of sympathetic nerves (Lusardi et al., 1999, Mancia, 1993). The activation of sympathetic nerves exacerbates the increases in blood pressure, and also increases the excretion of urinary norepinephrine in the morning, after a night of sleep deprivation (Somers et al., 1993, Jones et al., 1982). Pak Jono reported in one of my visits that he mostly had difficulties going back to sleep after he finished his soya bean grinding duties. The family supported this observation during the interview, saying his sleep deprivation may impact Pak Jono's hypertension. In the interview I asked about the management of hypertension, and their answers included 'patients should have proper sleep and

rest'; but then they revealed that Pak Jono was sleep deprived because of the soya milk production. When I asked them during the interview what should be done to control hypertension, the family members stated:

"Pattern..lifestyle..the sleep pattern! Rest". (Mila)

"He lack sleep, it's because of soya milk" (Bu Karti)

"Lack of sleep is the cause". (Mila)

"Soya milk, made him lack sleep". (Bu Karti)

"Blood pressure increases" (Mila)

Pak Jono and his family were not concerned if sleep deprivation is a determinant in hypertension, even though they understood about it. This attitude appeared to be that earning money seemed more important than Pak Jono's health, and as a result it means he has to compromise his night's sleep, so getting less than he needs. Becker (1976), when considering the economic approach to human behaviour, suggests people believed that long life and better health are important, but they may sacrifice that good health and long life if there are other aims that they think are more vital:

"there is an 'optimal' expected length of life, where the value in utility of an additional year is less than the utility foregone by using time and other resources to obtain that year"(Becker, 1976, p.9)

The conflicts experienced by Pak Jono related to whether he should sleep at night as usual, versus doing late night work to earn money for the family business. Pak Jono has been identified with hypertension, but he is also very committed to his work, a mind-set which results in compromising his sleeping patterns. His behaviour is not necessarily because he is ignorant of the consequences of his actions, or is unable to comprehend the information he possesses; it is simply that he thinks earning money is more important than having a proper sleep.

Pak Jono has controlled his hypertension mainly using medication. He has taken the medication regularly, even receiving awards from the clinic due to his

punctuality and regularity in visiting the clinic for blood pressure checks. However, his non-pharmacological approach still needs improvements, particularly as he did not seem to have much control over his conduct. His hypertensive condition was being aggravated by both his sleeping patterns being interrupted, as well as by his diets. Further evidences for Pak Jono lack of control for his diets is discussed in section 5.6 (page 289), due to his wife preparing the food for him and she admitted she did not really reduce the amount of salt in his food. Bu Karti's reason for not providing the required hypertension friendly foods for her husband was because she was too busy making the soya milk and preparing foods for her catering enterprise. Once again the goal of financial fulfilment played a significant part in influencing her during the food preparation. This couple are aware that their health is likely to decline when they get older; thus in their minds it is important for them to keep earning. By doing so they will have the support of savings to protect them against conditions they might meet in the future.

When the population was surveyed during 2008-2010, high poverty rates was found among the elderly age groups (Arifin and Ananta, 2009). Meanwhile, the Indonesian government has so far failed to provide a comprehensive primary healthcare security scheme for the elderly. Instead the focus has been on the wellbeing of other categories, such as children and motherhood instead (Kadar et al., 2014). In such circumstances the Indonesian elderly still feel it necessary to earn money while they able to do so, in the hope of having a more secure future. As for Bu Karti, earning money is more important than other activities, such as cooking 'special' or appropriate foods for her husband. The evidence was she has two sources of income: i) working for her daughter Mia, as well as ii) running her own small catering business. Therefore, she reported that she did not have enough time to provide 'special' foods for her husband. In a study about economic wellbeing of

the Javanese elderly Rudkin (1993) found that the women have always experienced economic disadvantages throughout adulthood, because they are unlikely to have earned an income. Even for those women who do have an income, it is almost certainly going to be less than the incomes received by men. Other than that Rudkin (1993) also pointed out that women receive lower remittances among older people who are dependent on kin; furthermore women tend to be less able than men at accumulating resources during adulthood. This concept may explain Bu Karti's situation; she never had a work income that she could accumulate as a resource in her later life. For her it is very important to keep working to secure her future.

5.4.3 Summary

Financial and economic considerations are two of the most important determinants in health and wellbeing (Naidoo, 2016). Financial circumstances not only influence health care management when the patient is without adequate funds but can also do so when adequate finances give more power to place the patient on an elevated hierarchy; thus awarding them more agency. Financial hardship in one example resulting from conflicts between family members, ultimately concluding with the erection of barriers preventing communication, and thus support, from between the members involved. The lack of support caused the patients to compromise their diets in order to have sufficient funds to meet the family's other needs. Meanwhile, the participants who earned money tended to exert more power in deciding their diets, and as a result usually became resistant to healthy diets, because they have more agency to choose their favourite meals. Therefore, financial circumstances are a significant aspect of processes in a family system, as they oblige the participants to compromise their diets, due to their inability to afford healthier meals for daily consumption. Equally, those who were financially comfortable failed to control their diets, influenced by the delights of over-indulgence, at least until their money ran

out. This outcome was because the more advantaged participants would have more agency in choosing their meals, at least while they had the funds to do so.

5.5 Stress and the coping process

Stress is defined as *“the state manifested by a specific syndrome which consists of all the non-specifically induced changes within a biologic system”* (Selye, 1956, p.54). The agents that can or do produce stress are referred to as the stressors. Hypertension is known as a condition that is influenced by various mechanisms. Nervous and emotional stimuli can make powerful and harmful impacts on the cardiovascular system (Selye, 1956). Nervous stimuli that result in emotional stress have been related to increases in blood pressure; the more persistent the stimuli the greater the blood pressure's elevation (Larkin, 2005; Selye, 1956). Emotional stress triggers the liberation of adrenalin that directly affects the sympathetic nerves in the human cardiovascular system, resulting in hypertension (Selye, 1956). Most of the patients that I observed were living with hypertension because of their age and or because they genetically inherited the condition. However, in line with Selye's idea of stress in the General Adaptation Syndrome, emotional overstimulation is probably another significant cause for the hypertensive patients' condition.

Stress has been recognised as a major risk factor in blood pressure elevation (Larkin, 2005, McEwen, 2006, Mustacchi, 1990, Spruill, 2010). The development of hypertension caused by stress involves responses from the sympathetic nervous system, which releases catecholamine so leading to increases in heart rate, cardiac output and blood pressure (Spruill, 2010). It would be misleading if individuals' stress is isolated from the actions of those with whom they form relationships. Social networks have also been acknowledged as important stressors, especially within family relationships (Kawachi et al., 1996, McEwen, 2006). Stress can be the

result of an individual's problems that affect the whole family, as that form of social unit is a system characterised by a feedback loop. It means when 'a part' expresses an action then there will be reaction from the 'other parts'. The description of stress experienced by the family is labelled as *family stress*. Family stress is defined as "*a disruption in a family's equilibrium*" (Boss, 2017, p.2). In a family stress model, a stressor or the cause of stress is defined as:

"a life event or transition impacting upon the family unit which produces, or has the potential of producing, change in the family's social system" (McCubbin, 1983, p.8).

Stressors that exist within the family may have caused impact upon a family's boundaries, goals, patterns of interaction, roles, or values (McCubbin et al., 1983). The family as a unit often experiences stress, especially when the family loses, or anticipates losing, of one of its members. This 'inevitable' event will change the family's functions as it goes about daily life. Conflict is one of the indications that a family is stressed, either by cause or effect (Tomlinson et al., 2012, p.706).

An engineering metaphor may be used to describe family stress as 'like a bridge'. A bridge experiences forces pressing, pushing, or pulling because of the vehicles that use it (Boss 2017, p.2). Similarly, family stress is inevitable and normal, yielding positive results, negative results or perhaps both. The author emphasises family stress gives negative results when physical symptoms occur in individual family members (Boss, 2017).

Minuchin (1974) suggests, family as a system is changing due to pressure from its members and society to maintain continuity. Responding to the changes experienced by the family requires constant transformation, and this process creates stress whilst attempting to accommodate the new situations.

Family stress is shaped by two contexts: external and internal (Boss, 2017). The external context include the environment or family's ecosystem that family has no control, meanwhile internal context include elements that family able to control

(Boss, 2017). Boss (2017) adds the internal context is composed of three dimensions: the structural, psychological and philosophical contexts. This study focuses on the psychological context, which emphasises the family's and its members' mental and emotional perceptions of an event (Boss, 2017). The discussion of psychological context for this study focuses on some issues experienced by its members that affected the whole family.

Feedback as the result of a family's interrelationship structure appears to influence hypertension management, especially its relationship to stress, either as the source or the support to manage the stress. In correspond to the agency-structure concepts, not that the structure determine the agency but structure gives influences the agency (Giddens, 1986). The findings revealed a number of structural forces at play in enabling and constraining the agency of hypertension patients in managing their stress as they interact, engage and live with the family members. Initially the family as a source of stress is explored; with particular reference to incidents considered as stressors that occur within the family. This is followed by an outline of findings relating to family members supporting the patients to manage their stress by providing a calm environment and promoting regular gathering with family members just to share problems being experienced. Finally, the degree of autonomy experienced by the family members affected by hypertension, in influencing the range of stress management opportunities available to them, is explored.

5.5.1 Family as the source of stress

As a system family experiences various changes throughout the life span, such as the change of roles due to the addition of new family members, the loss of family members, or the transition due to growth and development such as teenage transition (McCubbin et al., 1983). Thus the family cannot be separated with various

unpleasant or challenging events that may become emotional stressors for all the family members (Boss, 2017). And the stress resulting from those events has exerted significant influence on the patients with hypertension. However, those patients could not control the events because the sources were the family members. The patients could not avoid stressful experiences because they are tied as a family and interact with the members every day. The following illustrations are from Pak Dony's family, Pak Agung's family, and Bu Lely's family.

Pak Dony's family is from a Chinese ethnic background, and he is the third generation since his family moved from mainland China to Bali. On the first visit to Pak Dony's family, I found out that he started having increased blood pressure since his wife passed away in 2009. The wife's death was caused by stroke, triggered by hypertension. The stress due to her death and also the funeral ceremonies had caused him many sleepless nights and he believed that sleep pattern disruption was causing the increased blood pressure. Pak Dony, had a check at his doctor and found out the systolic blood pressure had gone up to 200mmHg. He repeated the information during the interview:

Since the beginning I never felt I had hypertension, I told you before, it was because (too much) sleepless, stress, and so on, the physician said 'owh it's 200 (mmHg)'. I maintained (normal blood pressure) since then. (Pak Dony)

The stress he experienced was because of his wife's sudden death. She did not show any illness and suddenly fell into a coma, and within two days she died. Pak Dony, was not ready for his new role as a single parents, with daughter Dina being only 9 years old at that time. He also still had to try to meet the other two children needs. His loss clearly triggered his hypertension, as bereavement is associated with the heightening of haemodynamic forces, and the blood pressure is still increasing for those who are not taking blood pressure medications (Buckley et al., 2011). The burdens that he used to share with his wife have had to be managed

alone since then. His children could not provide enough emotional support as they themselves were greatly affected by their loss (Elklit and O' Connor, 2005).

An additional stressor for Pak Dony was his dispute with his son which happened not long after he lost his wife, resulting in an estranged relationship between father and son that, until now, has not been resolved, as he told me during a trip to the cemetery. He was disappointed with his son for not finish his bachelor degree, while Pak Dony really want him to have a degree. Traditionally, Chinese family has been long known for their male line kinship system, and placing men as the higher gender than women (Thornton and Lin, 1994). Parents will invest more in their sons, as for education, than in their daughters. Sons are expected to support their parents financially even after they have their own family, whereas a daughter will live with her husband's family and leaves the natal family (Xie, 2013). Thus Pak Dony was still extremely upset with his son because he might not get a good job that could support the family. The dispute between Pak Dony and his son was also a stressor for Pak Dony because he considered he had lost his son. Every time he thought about the son it triggered Pak Dony's disappointment, as I observed in our conversation when he did not want to talk about his son any further and changed the conversation immediately. Pak Dony experienced an ambiguous loss, a loss in daily life that is not readily or easily recognised by society (Betz and Thorngren, 2006). It is ambiguous because physically the son is absent yet psychologically he is present (Boss, 2009). Such an ambiguous loss creates a stressful situation because of its uncertainty and unending torment (Betz and Thorngren, 2006). In Pak Dony's situation, he seemed not to want to forgive his son, and might never know when he would see or talk to him again.

The death of his wife and his poor relationship with his son, whom he considered to be lost from the family, were all stressful experiences influencing Pak Dony's mental health. Stress management is not included in hypertension

management offered by the clinic, only medication. Family members, especially women, actually could give emotional support that might reduce individuals' stress levels (Lye, 1996, Thoits, 1995, Reid and Reczek, 2011, Valdez et al., 2013). However, gaining emotional support from his family might not be possible for Pak Dony. Sharing problems with his youngest daughter Dina, would not seem feasible. As a 17 year old girl, with no mother to relate to, at her developmental stage she prefers to spend time in her room, to show her independence, or more time with her friends, than with her father (Smith and Smith, 2015). The other daughter lives in another city, so he can only talk to her on the phone; she rarely visited him in Bali because she was busy working and studying in Jakarta. So, it seemed he could not rely on her either.

Taking care of teenager daughter alone, is another issue that Pak Dony has to deal with in his daily life. In one of my observations, Pak Dony was really upset with Dina, because she went out with her male friend. Pak Dony and Dina had a small dispute at that time with her father saying that going out during the night time is inappropriate for a young girl, but Dina insisted on going out. Pak Dony finally approved Dina's request, although he kept murmuring and was clearly upset with what his daughter had done that night. The transition into adolescence is a very challenging stage for both children and parents, a stage viewed as 'storm and stress' (Arnett, 1999). The turmoil caused by their hormones during the early stage of adolescence can dramatically change both their behaviour and emotions (Buchanan et al., 1992). This change often causes the adolescent to be in conflict with their parents, exhibiting more emotional volatility leading to mood disruptions, and a susceptibility to engage in behaviour that potentially could harm them and other people (Arnett, 1999).

The personal changes of the adolescent become significant stressors for the parents. Putnick et al. (2010) found that parents' stress levels increased due to

parent-child problematic interactions during the junior member's transition to adolescence. In the case of Pak Dony and Dina, the argument they had on that evening was not the first, because Pak Dony mentioned he always reminded Dina to not go out after dark, as he was concerned for her safety, but she seemed to ignore her father's wishes. Dina's teenage behaviour potentially gave him another stressor, in addition to other problems he has experienced with his son and the loss of his wife. Moreover, he is the one who has to watch his daughter, no other family members that he can rely on for that. In an ethnic Chinese family, mothers predominantly will give lessons to daughters about their cultural roots such as cuisines, rituals, taking care the home and family, whereas fathers are responsible in giving lessons to their sons (Tan, 2008).

The implication here is that family issues seemed to be the main stressor for Pak Dony; the loss of his wife, the problems with his son and daughter. He appears to be receiving no adequate emotional support from the family, a case which highlights the importance of the family influence on the incidence and control of hypertension.

Another example of family as the source of stress was observed in Pak Agung family. This extended family is more complex, compared to the other families on this study. The family members perceived their situation as complex and complicated, and they believed their problems influenced Pak Agung's blood pressure. Agung's family seemed to experience more problematic issues than other families. Similar to Pak Dony, the first source of stress is because Pak Agung became a single parent since his wife passed away because of a stroke. Pak Agung and his family discussed the devastating impact the death of his wife and their mother has had on the family. He became a single parent, and was very doubtful whether he could raise his children alone when they were financially destitute. Pak Agung mentioned

in the interview, that the loss of his wife had devastated his life and caused him great stress.

"That's the cause, since my wife passed away I always think about it, I have so many things in my mind, thinking about my child who is still single, thinking where to sleep". (Pak Agung)

"Then the blood pressure spikes?" (AS)

"Yes, it's since my wife died, I think about cooking at home, what we will eat the next day, thinking about my kids at school, whether I can support them, nobody takes care of the house, sweeps the floor" (Pak Agung)

Similar to Pak Dony's case, Pak Agung's loss of his wife had *shattered* his family. The sudden loss changed the family's equilibrium into a chaotic situation that he doubted he could manage. The demand was too great for him to cope, because a role as a wife in a Balinese family has so many duties compared to the husband. Her duties include almost all the household duties, child rearing, and in addition daily offerings and the complex offerings for the frequent ritual ceremonies (Suryani, 2004). Suryani (2004) adds that the women in Balinese society often have to work as well, so they can contribute to the family's income to balance the family budget.

The loss of his wife was really a huge blow for Pak Agung and his family, an event perceived as a very dark time for the family: "the sky seemed fall apart!" Pak Agung had to replace part of his wife's roles in both the family and society. His sons were still too young at that time, so there was no daughter in law that could replace the position of his wife. Thus, he believed these stressful conditions had caused his blood pressure to spike.

Buckley et al. (2011) suggested haemodynamic changes occur due to bereavement, and as for those who does not take their medication, their blood pressures will continue to increase. Pak Agung had experienced increased blood pressure when he was young, but he never treated it properly. That condition has now become worse since his wife died. Similar to Pak Agung, the other family members also believed that all the problems the family experienced have caused

Pak Agung's blood pressure to increase. The family problems being the reasons for Pak Agung's hypertension were consistently cited both during the individual and dyadic interviews.

Rina, Pak Agung's daughter in law who I interviewed individually, mentioned that Pak Agung's high blood pressure was mostly triggered by various family problems:

"Usually when he kept quiet, he started to (h) 'what's wrong Pak? 'I don't know I felt dizzy', ah it's your blood pressure, it's OK, sometimes it goes up or down, maybe because of the burden in this house. When he has problems he can't sleep, like that, when he has problems he can't sleep. Family problems, that's all, family problems" (Rina)

During the interview Rina did not want to elaborate upon the problems this family experienced, but similar to the other family members, she emphasised stress as the result from bereavement was the trigger for Pak Agung's hypertension in the beginning of his condition. Throughout the observation, I managed to observe and gain information related to their family problems. From Raka and Rina I obtained information how problems after problems continuously hit the family. In the interview with Raka he suggested that other than the loss of his mother, the death of his sisters, and sisters' family problems have influenced his father's health, especially his hypertension. Meanwhile Rina mentioned that her troublesome sisters in law have influenced Pak Agung's health especially his hypertension. On top of that, she added poor relationships between her husband and Yoga (Pak Agung's younger son) created disputes between them, usually because of small issues in the family, such as house cleanliness. Constant disagreements, even small ones, created an uncomfortable situation in the family that potentially affected Pak Agung, by ensuring that his environment is anything but stress free.

I had the chance to observe situations that involved tensions in the family and created uncomfortable situation for Pak Agung. The first situation was when I came

to their house, I met Pak Agung lying down on his lazy chair under the tree uninterested. He usually greets me enthusiastically with a smile, but not that day. I asked him whether he went for the gymnast at the clinic earlier, and he said did not go. When I asked the reason, he said too lazy to go because it was too easy for him. He used to a badminton athlete that had involved hard training. However, he then told me that one of his daughters had a dispute with her husband and they planned to separate. This made him so upset and sad that he could not concentrate and lacked any motivation to leave the house. The stressful condition that he experienced due to the daughter's problem influenced his motivation for the daily activities. His response to the problem was a representation of distress, the demands on body and mind were too great, and he simply did not have the personal resources to deal with them in an appropriate way (Von Onciul, 1996). Von Onciul (1996) suggests a stress response is actually healthy as long as it keeps people motivated and adaptable. However, when the emotional stress level is too high it causes the host to become exhausted, manifesting signs of excessive stress including a lack of interest in general, and reduced attention to personal issues such as exercise or grooming.

The situation in the house that afternoon seemed very gloomy. When I talked to Rina, she told me the same story, almost cried, and expressed feeling very sorry for her father in law because he had experienced similar situations on several occasions. She was disappointed that her sisters in law always made their father sad, because it means the problem would cause him sleeping difficulties as it was worrying him, and would eventually influence his health. At one point the family was the source of the stressor, but on the other hand they can also be the closest emotional support for the individual members. This support dimension was evident as when Rina indicated her concern that the never-ending problems may start to harm her father in law's health.

The daughter's separation became a huge stressor for Pak Agung because of the stigma of being a widow in Indonesian society. In Indonesian society, a woman should only have sex with a man she is married to; thus being a widow or '*janda*' is strongly stigmatised (Parker and Creese, 2016). In Indonesian culture, a *janda* is associated with a woman of 'unprotected' status, being perceived by many that she is available for sex, because she is sexually experienced and unattached (Parker and Creese, 2016, p.2). The stereotype of sexual availability has the consequence that she is susceptible to sexual harassment and unwanted attention, in turn leading to 'presumed promiscuity'; thus a *janda* tends to be labelled as immoral, and it brings shame to the family (Mahy et al., 2016, p.65). Other than that, being a *janda* not only makes a woman open to stigma, but she is also financially vulnerable because the patrilineal descent system and virilocal residence patterns force her to leave the marital home. She loses her partner but also the important source of family income (Putra and Creese, 2016).

The second situation I observed was a dispute between Pak Agung's children and their friends. That afternoon I had an appointment with this family to have an interview, but the interview was interrupted by this incident. The dispute was about money, that someone (pseudonym: Putu) had given a motorbike to Raka as payment for a puppy, and the motorbike was then used by Raka's sister. However, at that day someone else claimed the motorbike as theirs, apparently Putu gave someone else's motorbike to Raka. I could see anxious faces of the family members when the sister came with high voice tone saying that a guy has claimed the motorbike as his. Raka was clearly upset and started getting angry. I had just started recording Pak Agung, 5 minutes before the daughter came, he looked upset and worried, I could see his face turned stiff, the smile has gone and focused on the guests. After everybody had gone he said to me, with a big sigh:

"It happens frequently" (Pak Agung)

It was not the first time such a thing had happened in this family. They were frequently shocked by unpredictable situations that kept the family members in a state of constant worry, especially Pak Agung. According to Yoga, his father could not sleep if there were problems, and mostly the sources of those problems were the family members. Yoga gave an example when the nephew's behaviour disrupted his father's sleep:

"So, he could not sleep if he has a problem?" (AS)

"Yes, he could not sleep, awake all night "What's wrong Pak?" ahh, but he won't (answer), 'too hot'. I actually knew if he has problems then he could not sleep. Yes, if he has problems, such as my nephew, Eka, when he's out, riding his motorbike, 'Why he's not coming home yet? Can you call him?' he would say that, 'He will be home soon, he will find the house' I would reply" (Yoga)

Pak Agung was always worried about his family, especially Raka and Eka. Raka's job frequently required him to leave the house at night, or for a long period of time, which caused the father worry about his son's safety. Meanwhile the grandson (Eka or who?) is a rebellious boy; he failed to finish high school because he frequently skipped classes. Also the grandson had previously left the house and lived at his friends' places for several months, finally coming back because he did not have money left. Thus Pak Agung was always worried and could not sleep if Eka had not returned home at night. The adolescence transition played its part in this stress filled situation. The unstable hormones during this period have changed the personalities of the adolescents involved. They become rebellious and resist adult authority, leading to yet more conflicts between them and their parents, or in this case: parent (Arnett, 1999). The everyday hassles and conflict between the parents and their adolescence children significantly increase parents' stress levels (Arnett, 1999, Kohn et al., 1991, Buchanan et al., 1992, Johnson et al., 2004, Putnick et al., 2010, Garnefski and Okma, 1996). Although, other than their 'raging hormones' the adolescents' behaviour is strongly related to and informed by their social environment, especially the family (Mason et al., 2017, Hill, 2012, Kaltiala-Heino et

al., 2016, Evans et al., 2016). Adolescents with a background of frequent family conflicts, and raised by a single parent, show increased levels delinquent behaviour (Evans et al., 2016). As in Eka's case, his biological father abandoned him when he was six months old, after his mother passed away, and since then he had lived with Pak Agung's family. Eka's environment was of a family whose members frequently experienced conflict, thus the family factor potentially had a significant impact on his unruly behaviour, in addition to adolescence transition.

The problems experienced by this family were seen to strongly influence the ability of Pak Agung to exert his agency in managing stress. Frequent problems experienced by the family members were the biggest stressor for Pak Agung. In addition, given that the problems often disrupted his sleep, and moderated his motivation to engage in physical exercise, it is clear that his family served as a source of stressors as well as challenges and barriers to his hypertension control.

Similar to Pak Agung's family, the separation of family members as the source of stress was also observed in Pak Gatot's family. Pak Gatot and his wife Bu Lely have both been diagnosed with hypertension, but Pak Gatot's hypertension was linked with his type 2 diabetes. Hypertension and diabetes are the end result of metabolic syndrome, and due to sharing common pathways which interact and influence each other, both conditions may develop one after another (Cheung and Li, 2012)

The couple reported that their daughter's separation had negatively influenced their health, in particular their blood pressure was increasing because of it. This couple live together with their daughter (Bintang), son in law (Darto) and three grandsons. During my earlier visit to this family, I noticed that the daughter had conflicts with her husband. She refused for her family to be included as participants in this study, because she never knew if her husband would be present. Also she made the point that in her opinion her children were too young to be included in this

study. However, I was able to understand the conflict she had with her husband when I visited the family to observe their meal preparation.

During my interaction with this family, I had a chance to see Bu Lely preparing meals for her family. She invited me to come to her house one morning. I went to their house riding my motorbike, and when I arrived there Pak Gatot opened the gate for me and said that their family had just been through a terrible time. I could see he was very sad from his swollen eyes. His son in law (Darto) just left the house, removing his grandchildren and all their belongings. I never saw him this sad before; he was always friendly and enthusiastic. But today I saw his sadness. I felt uncomfortable with this situation, but I still parked my motorbike in the garage because he asked me to. From his story it was evident Pak Gatot felt disappointed with his son in law, because he did not have a proper job; as a result the family's expenses were met by Bintang and also Pak Gatot and Bu Lely. Another thing that also made Pak Gatot so disappointed was that his son in law did not practice Islam properly; in particular he rarely prayed five times daily. It should be noted that Pak Gatot and Bu Lely were both very devout and followed the principles of Islam seriously, whilst also expecting their family members do the same.

He pointed the part of the house, where Darto and his family lived; it was empty with some small items scattered on the floor. Darto had gone with his children to his parents' house. Pak Gatot could not hide his sorrow; his thoughts were with the grandchildren and he was already missing them:

"I cannot believe he took the kids, I could not see them anymore" (Pak Gatot)

When he said that I could see his eyes widen and shed some anger; he could not accept that Darto had taken his grandsons. I also sensed his embarrassment for the situation, when he apologised that I had to see this situation happen. Shame and anger are common feelings for both the separating couple and their parents (Gray and Miyake Geron, 1995). The feeling of anger that Pak Gatot had was mainly

because he and Bu Lely have been taken care of their grandchildren and fulfilled their needs, but the son in law had dared to take them away from the grandparents. In Javanese society, grandparents and grandchildren have a very close relationship, and the grandchildren are considered by the grandparents to be 'their' children. This perception is informed by the fact that many grandparents at times take the full responsibility of caring for their grandchildren, up to supervising their education and even arranging their marriages (Koentjaraningrat, 1985). This situation hurt both Pak Gatot and particularly Bu Lely because, although they did not take full responsibility, the grandchildren spent more time with them than with their parents. The grandparents were the first people the grandchildren turned to if they had difficulties. For example, I saw Pak Gatot help the elder grandson with his homework, and Bu Lely played with the younger grandson and comforted him when he cried or was annoyed by his brother. Bu Lely also told me, one day she could not find her youngest grandson, because he played with his friend quite far from their house. She became extremely worried because none of the neighbours had seen him, but then luckily one of their neighbours saw the boy and brought him home. Since then Bu Lely asked her daughter to advise the grandson not to go too far from their neighbourhood, otherwise she would not be able to take care of him anymore. Even though taking care of grandchildren can be stressful and tiring, both Pak Gatot and Bu Lely loved their grandchildren and were very attached to them. They felt a particularly painful loss when the boys' father took them away from this old couple. Grandparents enjoy grandparenthood activities which are generally considered as pleasurable, so when they cannot do the activities anymore, the consequence is not only physical but can also result in emotional problems such as stress, grief and anxiety (Drew and Smith, 1999, Kruk, 1995, Kivnick, 1982).

After telling me about the situation that morning, Pak Gatot then asked me to go inside to see his wife. Inside I met Bu Lely; she told me the same story. Similar to

her husband, she was also extremely sad that their grandchildren children had experienced such an emotional situation at such a young age. It appeared she was feeling guilty, because she regretted what she had done to Darto in the past. She tried to find the reason why he had taken the grandchildren away; she guessed it was because she and her husband had always told him to pray regularly:

"Maybe because we always ask him to pray, I don't know" (Bu Lely)

When we talked, I heard the grandson's voice approaching; it seemed they left something important behind and had to go back to take it. At first I thought only Pak Gatot and Bu Lely were in the house but Bintang, their daughter, was also at home. She came out to see me; I could see her swollen eyes because she had clearly been crying. She hugged me and apologised for letting me see this situation. I was uncertain what to say, so I tried to reassure her with "It's OK". I heard Darto asked Bu Lely about a photo, but she did not know about the photos he talked about. The younger grandson cried and said he wants to stay there with both his parents. I felt so sad to see a little boy wanting his parents to still be together. I can imagine how the other family members must be feeling much sadder than me. I saw Bu Lely rushing to her grandsons and comforting them.

The grandparents seemed, and in one sense probably were, helpless. They could not interfere in their daughter's life; as witnessed when Pak Gatot and Bu Lely did not try to hold their grandsons even though the younger one cried when Darto forced him to leave the house. The eldest grandson, did not say anything but simply followed his father. Pak Gatot and Bu Lely tried to make the situation as normal as possible, but actually they were very upset with what their son in law had done to the family. In terms of affinal relationship in Javanese society, or relationships developed through marriage rather than descent (Calhoun, 2002), there are differences attitude between parents in laws and their son and daughter in law. When a couple live together with the wife's parent, then the parents, especially the

mother of the wife seldom quarrel with the son in law, because they respect the son in law as the head of their daughter's family, and all disagreements between their daughter and the son in law are not their concern (Koentjaraningrat, 1985). Meanwhile, Koentjaraningrat (1985) added that when a couple live with the husband's mother, there will be more possibilities of friction between her and the daughter in law. For Pak Gatot and Bu Lely, they could not interfere with the daughter's problems, even though the situation was so upsetting for them. Their disappointment was expressed by Bu Lely, when I asked her whether I have to rearrange another time come because I felt uncomfortable with the situation in the house that day, but Bu Lely said we just continue what we had planned before. It seemed that she needed someone to talk to about her family problems. She kept telling me about her daughter's family; sometimes she regretted what she had done to Darto. At other times she blamed her son in law for the situation, but apparently, she still could not believe what had happened to her family. The decision taken by Darto to leave his wife had shocked the family, especially when he took his sons with him. Parents are usually unaware of the state of their children's marriage; so when a separation occurs they feel shocked, surprised and devastated, resulting in significant levels of health damaging stress (Hamon and Cobb, 1994).

After that visit, Bu Lely invited me to come when her family held a gathering. I came to their house on the date she suggested, I came very early in the morning, and helped them prepare the meals. She introduced me to her relatives who came to the gathering. In Javanese society it is common for a family to gather with their kin group, including the consanguinity and/or affinal related. During the meal junior family members will be introduced to other relatives, and/or there will be discussions about important matters that may involve the kin, such as a wedding (Koentjaraningrat, 1985). I could hear from my place in the kitchen if the families asked Bintang about her problems with Darto. Everybody wanted to know what

happened to them and the children. Bu Lely then entered the kitchen and told me that Pak Gatot had suddenly developed a stomach ache. She assumed it was a sign that he was so stressed by Bintang's situation, particularly as everybody finally knew about the problem. She whispered me that the problem had affected her too. When she had her regular check at Puskesmas, her blood pressure and blood sugar had increased, which she believed to be the impact of her daughter's problems:

"He (Pak Gatot) is having stomach ache, everybody was questioning him. For me all the vital sign measurements and blood sugar are increasing" (Bu Lely)

Bintang's problem had a strong impact to Bu Lely and Pak Gatot. Bu Lely believed the problem had caused her stress and changed her vital signs. The fact that they could not see their grandsons every day was the main stressor for the couple. The other stressor resulting from the problem was when the wider family circle knew about the matter. They could not hide their problems from the relatives, and this was a burden for them too. Divorce and/or separation related stigmas, such as shame and failure, not only affect the couple, especially the wife but also the couple's family (Konstam et al., 2016, Brown, 1982, Gray and Miyake Geron, 1995). Duffy (1982) suggests that in an extended family, a divorce of one of the family members can be a major source of distress for the other members. Parents may feel: a) that they failed in their role as parents, b) disappointed, c) helplessness and d) concerned about their grandchildren; particularly whether or not they will still be able to communicate with them (Brown, 1982).

In this study, the daughter's marriage problem led to the separation of the grandparents from their grandchildren, so creating a negative and disruptive impact on the grandparents' levels of hypertension. The strong stigma associated with separation in Indonesian society worsened the grandparents' distress. The grandparents were unable to cope with their distressing feelings of bitterness, anger, sadness and disappointment as the result of the separation; emotions which

potentially changed both grandparents' haemodynamic measurements, especially their blood pressure levels.

As a system, family members are interconnected; therefore the consequences of a major event to a family member, such as the case cited above, affect the other family members. Furthermore, those events result in a transition that has the potential of producing changes in the family system, such as in its boundaries, objectives, the interaction patterns, roles of the members and their values; changes that may be defined as family stress (McCubbin and Patterson (1983). The stress experienced by some families in this study originated come from the death of a family member, causing the family to adjust and adapt to the new situation: a husband loses his wife, children lose their mother, and grandchildren lose their grandmother. The hypertensive patients are usually the ones most affected by the event, as their roles often change massively, as seen in the cases of the two widowers presented in detail above. Secondly, the adult children's family issues, such as separation and divorce which are often strongly influenced by cultural values, have increased the impact of those events, not only on the families but also their kin. The continuous adaptation toward the changing equilibrium kept creating stress for the patients.

5.5.2 The family supporting stress management

Family as a self-controlled system, a property of the family system seen through the lens of cybernetic theory, has enabled the family members to provide feedback to maintain the steady state when there are forces that create disequilibrium within the family. In hypertension control, increased blood pressure is perceived as a negative force that requires the family members to respond in order to keep their parents' or husbands' blood pressure within normal range in order to avoid a stroke. Even though family members were the most important source of

stressors for the patients, on other occasions those same members supported the patients to reduce their stress levels. As the family members noted, a person with hypertension gets angry more quickly than the other family members. It was generally agreed the anger was a result of their parents feeling so distressed. The family members perceived small things, or just a small amount of stressor, could trigger their parent's anger; therefore, that emotion was frequently in evidence as a potential threat to the patient's wellbeing. Thus, anger could be a form of emotion that the family often had to face in daily life, when one of the family members was hypertensive. There is no agreement whether the anger was the cause, a symptom or the result of hypertension among the family members; however, it was clearly understood that hypertension could cause a stroke. The participants perceived stroke is a life-threatening condition that may lead to death or, if disability, then significant resources and strategies are likely to be required to manage such a patient. Therefore, the family supporting the member with hypertension should strive to reduce environmental stressors by minimising conflict so their parents/patients will be less angry, and so less open to any unwanted impacts on their mental or physical health.

When the family members knew that their parents or spouse had hypertension, they were aware they needed to avoid friction or clashes and keep the atmosphere in the house as calm and peaceful as possible. The family members always think creating an argument with the patient is useless and at the same time harmful to that person. Therefore, avoiding an argument is the best way when interacting with a person who has hypertension. Avoiding an argument is the most common strategy for creating a favourable situation in the house for the study's participants. The family members preferred to prepare themselves prior to conversing with the patient or to be very careful and cautious when talking to that patient in order not to 'rock the boat' in any way.

Mia, Pak Sadu's daughter provides a good example of this caution when speaking to her father. Mia was aware that her father, Pak Sadu, can be overly sensitive; a condition she believed was the result of his hypertension. Sometimes, her father misunderstood what she said, so she decided to be very careful when talking to her father. The following excerpt is from an interview with Mia:

"People said someone with hypertension is somehow sensitive, right? Mostly they are sensitive. Their emotion will be (her hand went up), directly like that. It's not the real meaning, but he gets it differently because of his blood pressure. That's why I will be like 'I don't need to do that because he has hypertension,' that's why I said I speak carefully" (Mia)

Mia was just divorced from her husband. She was living with her parents, but the parents became anxious about her after the separation, because sometimes she just stayed in her room and cried. When it happened the parents would start questioning her, meanwhile she actually just wanted to be alone, and then the parent and daughter would start arguing with each other. She did not want to always be confronting her father and a burden to her parents; therefore, she moved out and lived alone to avoid the arguments. The following excerpt is from Mia's interview.

"Well I had that problem lately, I feel bad for my father, as he can't be too stressed. I am afraid if I live there, if (he) sees me cry all the time, he will think too much about it. That's the problem. ((He asked)) 'Do you really need to move out?' I said 'Yes, so I can live close to my shop'. It's because I feel pity for him. I..., the problem is he always curious, he sneaked a peek on me 'Why is she always stay in her room?' he would asked. And sometimes, if (he) heard it 'Why is she crying?' that's what I worried about, how if he sick because of me being a cry baby. Well maybe similar to you, if you have a problem you must cry. There's no guarantee people will always see us happy or vice versa, I just don't want him overthinking my problems, that's the point. That's why I chose to move out" (Mia)

As discussed above, divorce is strongly stigmatised by Indonesians, including the Balinese (Mahy et al., 2016, Putra and Creese, 2016, Parker and Creese, 2016). Divorce and separation of adult children is a big stressor for their parents. In Mia's case she was aware that her issue could become a significant stressor for her father

that may influence his blood pressure by increasing it. Thus her effort to protect her father from stress related health issues was by living on her own, thereby providing a calmer situation in her parents' house.

Avoiding arguments in order to prevent patients from distress by providing a less conflict-filled situation in the house was also the strategy adopted by Karno and Eka. Karno is Pak Gatot's eldest son ; meanwhile Eka is Pak Agung's grandson. When I interviewed Karno he told me he did not want to burden his parents with his problems, because to do so might create conflict. He decided the best idea was to solve his problems without involving the parents in order to keep the situation under control. This is what he said when I asked how the family had controlled hypertension so far, and he emphasised his strategy in supporting his parent:

"For me, the most important thing is that I've never bothering them, and never burdening them such as never give them problems, the rest just normal things, the usual life. Just like this, just normal Mbak, not too...not too burdening that's all so that the parent won't overthink" (Karno)

Avoiding exposing problems to parents is very important as a precaution against overthinking by a patient that can lead to stress generation. Meanwhile Eka tried to create a less stressful situation by being obedient to what his grandfather expected, so preventing any upset. The following excerpt is from Eka's interview:

"Sometimes I clean up the house, to stop my grandmother from getting angry. It clears up her mind and keeps her calm, for example when I was asked to make coffee then I would do so" (Eka)

Even though Eka was rebellious, he actually tried to respect and obey his grandfather, in order to minimise Pak Agung's levels of stress. Dellmann-Jenkins et al. (1987) suggest teenager aged 13-18 years have a close relationship with their grandparents because teenager view their grandparents have important roles in roles in their life, thus grandparents are companion for teenager. In Eka's case, his

grandfather is also his parents, and for him Eka could only give emotional support to relieve his stress

Avoiding argument with the parents or older family members is a form of respect and honour shown by children to their parents. Having arguments with parents or even giving an order to parents, especially if a parent is ill, would be considered as disrespectful to the parents and that is totally unacceptable behaviour in Indonesian culture. For example, Karno mentioned it would be better to make the parents happy when I asked about his support for his parents who were experiencing hypertension:

“Yes, just to make them happy Mbak, because it will get unpleasant if we don't give them what they want” (Karno)

“Giving them what they want” suggests Karno did not want to create conflict or argument, because conflict with parents would be nasty, a situation he did not wish to create with his parents. Moreover when such behaviour could potentially trigger his parents’ hypertension, it would be unacceptable as such conduct would challenge both social and religious values.

Indonesian children have to respect and honour their parents, even if they are independent financially and married (Albert et al., 2005). Children are expected to be obedient, polite and respectful to their parents from when they are approximately six years old by using strategies such as: a) making promises, b) scaring the child by telling about punishments waiting for them in the afterlife, c) supernatural punishments, and d) shaming the children in front of others (Albert et al., 2005, Mulder, 1989, Zevalkink and Riksen-Walraven, 2001). For the Balinese Hindus, children are always considered indebted to their parents, because the parents have helped them to be born into this world so they can redeem the result of deeds in the past life (*karma pala*) (Eiseman, 2011, Hobart, 2001, Gottowik, 2010, Geertz, 1975). The punishment that the parents always tell their young children if they are not

obedient is called *tulah*, that can be received during their life and after life (Arsana et al., 1983). Arsana et al. (1983) adds that the punishments someone can experience in their life include: a) they will always unlucky, b) they will have difficulty obtaining offspring, c) they will have financial difficulties and d) they will suffer from diseases. Meanwhile for the afterlife punishment, someone who disrespected his or her parents during their life will be hung head-down over fire. Whilst Javanese children are never considered in debt to their parents, they have the obligation to honour their parents, and they are expected to offer things that attract their parents' goodwill (Mulder, 1989).

The children's efforts in providing a less conflict-filled environment for their parents included avoiding being or creating burdens for their parents to deal with and trying to make them happy. This peace strategy was influenced by the value of 'respect to parents', which allowed the children in this study to help the patients in their families to manage their stress. Meanwhile, the closest person to the patient is normally his or her spouse, so the spouse is likely to be the primary carer; as such they will have developed their own ways of providing a less stressful environment. The following section discusses stress management provided by support from the spouse to the hypertensive patient. The sources of information are Bu Rena (Pak Joko's wife) and Bu Marni (Pak Sadu's wife).

Both wives said silence was the best way to avoid an argument. They prefer to keep silent when their loved one gets angry or tries to start an argument if they feel stressed. The spouses believed that when they go quiet, or keep quiet, the fight would stop; their husband becomes less angry and so their stress is controlled. Bu Rena shared during her interview that when her husband was stressed he would usually show his state in the form of anger. Initially the couple would argue, but finally she realised that arguing caused his blood pressure to increase, so she usually preferred to keep quiet to end the quarrels.

"I will go silent straightaway, that's it, I don't want to fight anymore. It's better for me just to remain silent when until he quiet then I will think 'Oh I was too emotional.' We then contemplate, if we did wrong we have to ask apologise, there's nobody anymore, that's why it is better if I am quiet, then he will say 'Sorry I was rude'" (Bu Rena)

The silence tactic she used seemed effective for soothing Pak Joko's anger, because both admitted their anger was just temporary, and they would forget the argument when they realised their mistakes. Similar to Bu Rena, Bu Marni usually faced up to her husband's anger, when he felt stressed. She would suggest him to control his anger, but he rarely listened; so to stop the quarrels between her and her husband, she would stop talking and go quiet:

"Your anger has to be controlled immediately, do not give in to your anger'. I said that; I always suggest to him whenever his blood pressure increases because he would get angry, too emotional. I quickly tell him 'control yourself', but sometimes he doesn't realise and is not willing to control his anger, yeah. I finally just go quiet, I don't pay attention to him, finally I am the one who just stays silent, ah forget it. If I go silent then he will be calm" (Bu Marni)

Family life is usually associated with emotions, and it is usually the women in the family who work on them by providing comfort and attention through unacknowledged efforts that makes family life and wage work possible (Devault, 1999). Their unpaid efforts and personal commitments has been conceptualised as 'emotion work' (Hochschild, 2012). The women's emotion work relates to the efforts made by the wife to ensure the family life runs smooth, from preparing to meet the family members' needs to maintaining harmonious relationships within the family (Devault, 1999). In marital conversations, women basic mechanism through which to communicate with their husbands when dealing with anger is silence (Benjamin, 1998). Women's emotion work, regarding a partner's anger, centres on silence; a technique which when applied usually soothes their husband's anger (Erickson, 1993, Hochschild, 2012). In the excerpts above, Bu Rena and Bu Marni both used

silence as the mechanism to pacify their husband's anger, which it did quite effectively.

Silence in marital conflict has been strongly related to women's oppression in patriarchal society (Benjamin, 1998). In Indonesian society, a woman will avoid open conflict with their husband, because challenging a male (or men) is seen as a woman behaving immorally (Brenner, 1999). Even though Bu Marni and Bu Rena said that they prefer silence to reduce potential causes of hypertension, that tactic was almost certainly influenced by society. In Indonesia women should not express their anger but are expected and obliged to bottle it up so that there are no obvious or shameful signs or her emotional state (Jaramillo-Sierra et al., 2017). Interestingly, even though the use of their hypertension control mechanism made it seem as if the two wives had accepted the conditions, as society expected, that silence was actually a tool to influence their husbands. This mechanism supports Giddens (1986) stipulation from 1986 that silence actually is viewed as a power demonstration. Gendron (2011) added that in a conflict, silence is related to issues of power; it can be used to disempower the party that is dominating a relationship.

The support family members provide for the patients is part of the feedback from the messages delivered by hypertension diagnosis. The family members believed stress to be the cause of hypertension; thus, creating a calm environment in the house is a form of support to prevent any serious impact of hypertension, especially stroke. A calm environment is usually created to avoid open arguments with the patient, so minimising potential stressors and levels of stress. For younger family members, such as the children and grandchildren, the value of respect for older people strongly influenced the members lack of willingness to create arguments with the hypertensive patients; particularly if or when the parents or grandparents were experiencing negative health conditions. Meanwhile for the spouse, especially the wives, the silence mechanism was chosen to avoid open

argument with the male patients, especially if the carer was a female. The wives' silence may be viewed as women's inferiority and/or deference towards their husbands, but in a conflict situation this mechanism can be used to disempower the dominating party or the husbands, which may often be the same thing.

5.5.3 Individuals' autonomy in stress management

Family, as an open system, receives influence from its surroundings. Family members receive various resources including information from their social environment. The interconnectedness, interdependence and interrelationships in the family help the family members to share the information they have received to the other family members. The social environment includes their social networking, involving their wider kin circle and peers, as well as religious institutions they are associated with.

In this study, family members have sometimes created stress within the family, as well as being a constraint to the effectiveness of the patients stress management strategies. Even though sometimes relationships among family members can be a strong and positive influence on the stress management performance of the participant with hypertension, there will be times when patients exert their agency to manage their stress by themselves. At those times the external environment usually plays a significant role for the patients. Most of them usually opted for meditation, which is often a part of religious and spiritual practices, as a way of reducing their stress. The second option was they would need to access their outer social network, such as going for family gatherings in a larger family circle and sharing their problems with them. One other option they could choose would be to share problems with their peers.

In this section meditation as a stress relief technique is elaborated, and from the data, meditation was especially chosen by the participant with Balinese Hindu backgrounds. This choice can be explained by tracing the history of meditation, in that it is rooted in Hindu and Buddhist traditions (Sedlmeier et al., 2012, Wisner, 2017). According to the religious approach or Eastern theoretical approach, meditation is a means to transform consciousness to focus on enlightenment. According to a Western theoretical approach, meditation is a means of self-regulation that is concerned with control over a person's well-being (Sedlmeier et al., 2012). Thus, Sedlermeier et al. (2012) concluded that meditation serves two purposes and can often be combined with, or seen as a part of, psychotherapy or/and personal and spiritual advancement. Meditation works by influencing the parasympathetic nervous system so the breath and heart rate gradually slow down, resulting in the maintenance of a natural state of relaxation (Verhaeghen, 2017). Such a state of relaxation then reduces the physical and mental tension within the individual that may help to reduce any harmful effects of stress (Rainforth et al., 2007).

In the earlier section (roles and responsibilities) it was noted that religion is an important aspect of the family system, an aspect that is recognised as a two-edged sword. Religion, with its associated obligations and duties, can be both a support and burden for Balinese families. In this section religious practices are shown as a support for the participants in hypertension control, especially the task of stress management. For example, Pak Hendra is involved in various religious and spiritual activities, and in those activities he has the chance to share and receive with and from his colleagues many pieces of information related to spirituality. He was also introduced to meditation through similar activities when he was younger, so meditation has become one of his strategies to manage stress. The following quote confirms his practice of releasing stress through meditation:

"I usually release it to unlimited space, (h). If I release it there it must be accepted, to the unlimited space" (Pak Hendra)

Pak Hendra regularly meditated and the 'unlimited space' he referred to during the interview was part of his meditation. Pak Hendra has been always interested in spiritual and religious activities that were able to give him the opportunity to enhance his skill in meditating. He also has the benefit in performing the meditation in that no tools or special equipment are required; he can therefore meditate when and where he chooses as a way to release all his problems.

Other than Pak Hendra who chose meditation as a strategy to manage his stress, mediation was also a strategy chosen by Bu Siwi to manage her stress, and she regularly meditated once her husband had guided her; she finally became interested in following his steps. The following excerpts from her interview were her answers when I asked about her strategy in managing stress:

"The most important is calmness, if we feel calm, then we can avoid everything, we can face everything calmly. Meditation is a calming our self-down, meditation is a self-contr." (Bu Siwi)

"When do you usually meditating?" (AS)

"At night, before I go to bed, if at this time (afternoon) is impossible, because for that we need to be really really calm, which at night is possible" (Bu Siwi)

She was introduced to meditation by her husband, Pak Dago, who always encouraged her to do the meditation daily. Meanwhile Pak Dago was introduced into meditation by his friends, with whom he usually makes spiritual trips.

Religion has always been recognised as an important aspect of family life, for its function in building personal intimacy, safety and emotional well-being (Krok, 2018). Meditation, which in this study is mostly related to religious activities, has also strongly influenced stress management. The practice is believed to create a personal tranquillity that is beneficial to soothing anger, and consequently reducing stress.

The second strategy chosen by participants needing to manage their stress involves socialising and sharing with friends and family. Both Pak Hadi and Bu Tari have both been diagnosed with hypertension, so when I asked them about strategies to manage their stress, the couple's answers were as follows:

"Usually I talk to my friends." (Pak Hadi)

"Family arisan, banjar arisan, village, region arisan" (Bu Tari)

Arisan is a rotating saving scheme, an activity that is well-known among Indonesian women, which involves both financial savings and social gathering (Papanek and Laurel, 1988, Biggart, 2001). Papanek and Laurel (1988) noted *arisan* is run by a group of women, and encourages the members to save some money over a period of the time. They meet regularly, usually once a month, to pay an agreed upon amount of money into the common pot. Every month, the members of *arisan* gather in a fixed place or a member's house, taking it in turns. During the gathering one or more members will draw lots to 'win' the money that has been collected. A member can join more than one *arisan*, it depends on her financial situation. Bu Tari, joined four different *arisan*: i) the family, ii) *banjar* (resident unit), iii) the village and iv) region; she was originally from the northern part of Bali, and so she joined a group of people from the same region.

5.5.4 Summary

You can choose your friends but the family cannot be chosen, thus it is extremely difficult, or even impossible, for individuals to escape from stress caused by their family. Family can be the source of stress but they also support individuals in their efforts to relieve such stress. Meanwhile, when the individuals have more agency then they have some opportunities to manage their stress. Some opted for meditation and religious activities, whilst others preferred to attend social gatherings. Those are illustrations of the dynamic processes evident in stress management for

patients with hypertension in a family context, as revealed by the respondents in this study.

5.6 Presence and absence of symptoms

The following section is the fourth subtheme that considers the family as a dynamic system in controlling hypertension mediated by the presence and absence of symptoms. The discussion of this subtheme is informed by general system theory (GST) in addition the protection motivation theory (PMT). This section describes the family members' support of the patients in controlling their hypertension was motivated by the fear of hypertension's impact, especially a stroke. However, it is important to note that levels of support correlated positively with the presence and absence of the patient's symptoms, rather than the person's general hypertensive classification. The discussion of the support is elaborated in the following sections.

The premise underpinning much health improvement work focusing on hypertension is that control lies with an individual to manage their behaviour and medication. Nonetheless, the results of this study demonstrate that control over medication and health behaviour is not static. Nor is it held by the patient alone, active support and control is also provided by the other family members, especially when symptoms are present. However, when there are no symptoms visible, as hypertension most of the time is asymptomatic, control will be kept by each individual patient. The following section discusses how the movement of control over hypertension management is influenced by the presence of symptoms. Hypertension is an asymptomatic disease that causes patients to usually ignore their condition when they do not have any symptoms. For some people, hypertension may give minor symptoms such as a headache and a stiff neck, but most of the time the individual has no symptoms. Moreover, symptoms can be managed well, and will disappear when the patients have taken their medication regularly (Bakris and Sorrentino, 2018, Mohebbi and Tehranchian, 2016, Woods

and Lafayette, 2010, Schiffrin et al., 2013). However, lifestyle changes in addition to medication have been proven to provide a greater impact in lowering blood pressure, than by medication alone (Angela Maria Geraldo et al., 2016, Appel, 2003, Campbell et al., 1999, Burke et al., 2005). Meanwhile, individuals do not live in a vacuum that separates them from their social network, especially family, where lifestyle changes mostly take place (Aschbrenner et al., 2012, Astin et al., 2014, Howes et al., 2013, Kautzky-Willer et al., 2012, Mollborn and Lawrence, 2018).

In a family system, the interconnectedness, interdependence and interrelationships of the members cause them to be part of the system exerting feedback when an event occurs. Within the cybernetic approach, feedback is related to power. That the power is circular means everybody exerts the same pressure in their feedback response. However, in a family with one or more hypertensive members, the circular power is unlikely to happen. For example, even though the family members are aware of the patients' condition but due to its asymptomatic character, they did not give attention for its control. Instead, the patient is the one who control mainly their medication and physical exercise, meanwhile other family members are the one who have more control on food preparations. This process shows a shifting control, that when the patients was not showing or complaining of any symptoms then the patient would not have control over the food and meals available. He or she would only have some control when the symptoms re-appear, at which times they could request the other family member to follow the hypertension diet's requirements, such as low salt. The patients usually perceived their hypertension as a personal threat to their well-being, but the family members perceived the same only when the hypertensive symptoms were present. In line with the protection motivation theory (PMT) motivation to protect oneself from danger occurred when 1) the threat is severe, 2) if the individual personally feels they are vulnerable to the threat, 3) if the coping response effectively tackle the threat, and 4) the individual is able to perform the coping response (Plotnikoff and Higginbotham, 1998, Plotnikoff et al., 2010, Plotnikoff et al., 2009, Rogers, 1975, Ali Morowatisharifabad et al., 2018, Bassett and

Prapavessis, 2011, Beirens et al., 2008, Bui et al., 2013, Flynn et al., 1995). Whether the family members intend to provide support for the patients, due to the severity of their hypertension, is discussed in this section by discussing the data through the lens of system concept and the PMT to gain an understanding of the family's involvement in hypertension control.

In relation to the PMT, stroke as the impact of hypertension, triggered fear for both the patients and the family members. The following interview excerpt from Bu Karti, during her individual interview, shows she felt stroke as the main threat if her hypertension was left uncontrolled. She would regret it if something happened to her husband as a result of hypertension, because Pak Jono has been very helpful to her.

"The hypertension? Yes, it's worrying, (I) will regret it if something happened to him, right? Well I am worried, I am, if the blood pressure increases then it causes stroke, results in this and that, right? That's what I mean, that's what I am worried about, we will regret it if something happened to him right? We will lose a lot, because he usually goes to the show, or somewhere else, I really rarely go out, 'Pak I need this' such as onions or something, (he) would run to the shops" (Bu Karti)

Bu Karti was worried about her husband hypertension because it might cause a stroke, and the fear then motivated the participants and the family members, such as Bu Karti, to take actions in controlling the hypertension. Although, during the interview and observations I found that control was mainly maintained by the patient and only briefly by the family members. The following sections discuss the mechanism of hypertension control by the patients and the family members, beginning with the topic of the brief support from family members.

The patients mainly have control over their medications and physical exercise, but the family has more control over food preparation and diets. The following interview excerpts and observation notes are from Pak Jono's family.

I visited Pak Jono' family and I was invited to see how they made the soya milk for their small family business. Pak Jono is the patient; he lives with his wife Bu Karti, daughter Mila, son in law and two grandsons. Pak Jono and Bu Karti were involved in the process of making the milk in their kitchen. Bu Karti showed me the foods she cooked for her family that day.

They had fried eggs, fried chicken, vegetables with coconut milk, crispy crackers (made of flour, soya beans, and dried fish), and a chilli paste condiment. There were no special foods provided for Pak Jono, with appropriate blood pressure-lowering ingredients. Our conversation was as the following:

"Who usually cook for the daily meals?" (AS)

"I mostly cook, sometimes Mila, but if we have orders for catering then I will definitely cook. The foods I cook just the same for everybody" (Bu Karti)

Another piece of information about their daily foods was also gained during the family interview. The patients, wife and daughter all had slightly different opinions about salt used in daily foods:

"For foods is a little tricky. (Mila)

"Yes foods." (Bu Karti)

"The salt, less salt." (Mila)

"It's so-so, I just put much salt." (Bu Karti)

"It's true that (foods) are less tasty without salt, feeling weak without salt, maybe just a little." (Pak Jono)

"It's true, I never separated (our foods), never separated foods, because I'm busy, so I never separated (foods), anything I cook that's for him too" (Bu Karti)

The illustration shows Bu Karti and Mila take the lead in preparing foods in this family, but Bu Karti has the main role, as Mila only occasionally cooks for them. Mila actually knew her father should reduce his salt intake. However, Bu Karti pointed out the foods would be tasteless without salt and nobody would like that. There were two different opinions among the family members. Mila acknowledged that salt is bad for her father hypertension, and Pak Jono seemed agree to perform salt reduction that his daughter mentioned. Although he implied salt is still needed for food, the quantity should be reduced for the sake of his blood pressure. Meanwhile his wife appeared to go against the opinion about the need for salt reduction. She agreed foods should be controlled in hypertension management, but not necessarily for the salt. She apparently did not want to be burdened by another task related to salt reduction in foods, because many times she emphasised she could not be bothered to prepare separate foods. She was too busy with all the tasks she had in the house, including working for her daughter making the soya milk, sometimes for food catering and also doing

her general household chores. She also suggested foods with no or reduced salt would be less tasty, and she did not want to compromise her food taste. She may have assumed that salt cannot make such a big impact on her husband's hypertensive condition, so she cooks with the same amount of salt and so far the hypertension still has not shown any symptoms.

As the member who has the main role in preparing foods, Bu Karti held control over meal preparation for the family, because she can decide the way she will prepare the foods without other's involvement. There was no evidence that she wanted to change her way of preparing meals for the family. Morgan (1996) suggested a family member who has more knowledge about food preparation include particular cooking technique, the knowledge about the combination of various ingredients, and the knowledge about dietary needs, represents a form of power and control in deciding the food a family will eat. In Pak Jono's case the other family members apparently just accepted Bu Karti's disagreement regarding salt content, as they believed Bu Karti had more knowledge about food compared to them. The evidence was when Mila did not respond to what Bu Karti said while she actually understood about the salt reduction, but she was apparently unsure about taking the initiative, saying salt reduction is "tricky". There was a hint of doubt in what she said, and in addition she only occasionally cooked for the family. Even if she had managed to reduce the levels of salt used in the family's food when she cooked, it would not be significant as her mother cooked most of the time. Pak Jono, as the patient, also accepted the way his wife cooked for him; raising no complaints regarding Bu Karti's statement about salt reduction.

The illustration above reveals the patient, Pak Jono, lacked control over his diets because the other family members who have the role in foods preparations, such as his wife and daughter, have more control over his meals than he had. Pak Jono's silent response seemed like an acceptance that if he insisted Bu Karti should provide less salty foods, it would burden her. She already had so many responsibilities for the family, thus let her control the diets to prevent her from stress that may cause conflicts between them. For Javanese families, couples tend to avoid conflicts if they have disagreement, their strategy in avoiding

conflict is by 'accepting without complaint' or *nerima* (Andayani, 2001). Conflict avoidance is the most commonly used strategy to achieve a state of *rukun* (harmony), because conflict is perceived as both negative and destructive (Ananta et al., 2014, Geertz, 1989, Jay, 1969). Conflict and intense relationships may arise as the result of chronic disease management. (Miller and Brown, 2005) revealed the responsibility of keeping diabetic partners on track with their diet management was a burden causing stress for their spouse which potentially challenged those couples' interactions.

The intention to modify diets when there were no symptoms indicating hypertension varied between members. The wife perceived that her husband was in good condition and she did not see any threat caused by the hypertension. Thus for her modifying diets was unnecessary. Furthermore, she believed the salt would not change anything, and she expressed her incapability to modify the diets on a daily basis because she was too busy with her work and other household tasks. Meanwhile, Pak Jono and Mila seemed to think that modifying diets for hypertension is important, but to actually do so was difficult, because they did not have control over meals on a daily basis. To enforce his diet agenda seemed impossible, because to insist would almost certainly trigger unnecessary conflict with Bu Karti. In this family system Bu Karti is at the top of the household hierarchy, even though Pak Jono is the head of the family. She has more power than the other family members in terms of catering and meal preparation; thus she is able to direct the other family members. Björnberg (2005) argues that women with their traditional role perform more household tasks than men, which enables them to gain more power and maintain their central position within the family.

On the other hand, sometimes when she had the chance, and Pak Jono expressed symptoms of hypertension or complained about his blood pressure, then Bu Karti felt she needed to modify her husband's diet. The following is an illustration from Pak Jono's family interview. In the previous part Bu Karti, was the one who decided the foods preparation in their house. Bu Karti stated earlier that she used a lot of salt in her foods, and exercised very

strong control over the meals in their house. Here is her response when I asked about hypertension related-food preparation:

“Well, when I want it (cook healthier foods), sometimes for me and him, I cook the cucumber, and tofu, ‘it’s your vegetables, cucumber and tofu’. I am too lazy making him juices, he does it, I usually (cook) vegetables, so his blood pressure won’t be too high, that’s my intention. I cook cucumber quite often, maybe because I like cooking, ‘the vegetables is for you and that’ only if I want, so his blood pressure won’t be too high. I reduce the salt, sometimes he said ‘the vegetable is too salty’, he moaned, ‘Ok I will reduce the salt’, but only if he complains, if not then I won’t. He usually complains ‘see you put too much salt on to the vegetables.’ He will be upset with me if his blood pressure increases” (Bu Karti)

The interview excerpts from Bu Karti demonstrate she mainly controlled the food preparation coercively, by saying she would cook healthier foods for her husband to prevent his blood pressure increased, “only if she wanted to”. She would reduce salt content only if Pak Jono complained about it because his blood pressure had increased. Bu Karti had very strong control over the food preparation practices in this family, although sometimes she slightly compromised the control when Pak Jono complained about the foods or his blood pressure rose. Pak Jono may be able to exert control on food preparation when he has symptoms, but his wife would regain control whenever she wanted to. In line with the power owned by women with their traditional roles, it is evident women can also assert their own needs and interests (Björnberg, 2005).

Ignoring the hypertension diet is a form of undermining or sabotage-type behaviour that may result in poor disease management outcomes (Henry et al., 2013). However, ignoring diets was also observed in five other families that were involved in this research. A question then arises about the patients who happen to have a role in food preparation, mostly female patients. The following section discusses this issue by using a situation observed in Pak Gatot’s family.

One day, I visited Pak Gatot’s family, as I had an appointment with his wife Bu Lely who had been identified with hypertension. I was there to observe food preparations in their house. I not only conducted an observation but became a participant observer, when I was asked by

Bu Lely to cut the vegetables and grind the spices to make the paste. When I finished my task, she tasted the paste and added more salt and also the monosodium glutamate (MSG) food enhancer. We cooked three meals, include fried spicy eggplants, fried soya bean cakes, fried prawn coated in batter. She told me the foods she prepared that day were to satisfy her grandsons' requests. They loved fried foods, especially prawns coated in batter. Therefore, she cooked those meals for them. As she said:

"I cooked what my grandsons love, they asked me to cook prawn the other day, that's why I have prawn today" (Bu Lely)

After the cooking, she then shared the food with me; a rice-filled plate with the three side dishes on top. The meal was delicious.

Before further discussion, I would like to highlight the use of salt for the meals. Bu Lely and Pak Gatot are patients who regularly attend weekly activities at the clinic. They fully understood that they need to reduce the salt in their daily meals because they were exposed to some information related to hypertension at the clinic, as Pak Gatot and Bu Lely said in our interview when I asked what they have done to control their high blood pressure:

"It's just the salt." (Pak Gatot)

"It's just salt" (Bu Lely)

"I mean reducing the salt" (Pak Gatot)

"I mean reducing the salt" (Bu Lely)

"I mean, if usually, we like salty foods, then now (need to cut the salt) sometimes the other would ask 'why is it plain?'" (I would say) 'It's because I have high blood pressure'. (Bu Lely)

"So, sometimes you reduce the salt?" (AS)

"Yes, I mean it will be more plain, if (they) want more taste then they can add more salt, I said that (to them) 'if I follow you all then I could not reduce the salt' I said it to them, so I cut the salt when I cook"(Bu Lely)

Based on the interview, Bu Lely indicated her awareness about one aspect of hypertension control and it seemed as if she could manage to cook with less salt. She even said the other family members should accept the taste of the foods or they could add more salt if they needed it. To clarify her statement during the interview, she gave me the opportunity to come and observed how she prepared the meals. During the observation, I did not see the practice that she said in the interview. She used both salt and MSG, with the latter

also containing sodium, and I did not taste the foods as plain, or as if they did not contain enough salt. I assumed the day I observed the cooking was not the day she reduced the salt content, as she mentioned she only did it 'sometimes'. Other than the salt, she mostly served foods that were fried. The fact that her grandchildren loved fried foods made her think it was best to give them what they loved rather than let them go hungry. It certainly looked as if this family had a lot more than two fried meals per week. Studies found that consumption of more than two fried meals per week is associated with a high risk of hypertension (Wang et al., 2010, Talbot, 2011, Gadiraju et al., 2015, Soriguer et al., 2003, Sayon-Orea et al., 2014).

Based on the illustration above, Bu Lely has the main role for food preparation in this family, as she cooks for the entire family on a daily basis. However, in term of controlling diets, her situation was not too different from Pak Jono. They could not ensure the continuity of diet modification on a daily basis. Bu Lely was unlikely to be motivated to modify her diets because she prioritised the needs of the other family members by prioritising her family's satisfaction regarding the taste of the foods she prepared. Providing the family with 'proper' food is very important for the food provider to gain a cultural reflection of how others appreciated and related to the provider (Ellis, 2018). Even though she said she needed to reduce the salt levels in her cooking, she did not implement that perception because she wanted her family to feel satisfied with the foods she prepared, and did not want them complaining about the 'tasteless foods' that she cooked.

The family's satisfaction is more important than food preparation for hypertension management. Björnberg (2005) asserts that even though a woman has the central position within a family, and is able to assert her needs and interests, she would place the family's common needs and interests first; a form of women's self-governance in the family. Furthermore, Bu Lely might understand that reducing salt is important to manage her blood pressure, but because so far she has never had severe symptoms of hypertension she is comfortable with ignoring the healthy well-being diets. During our conversations she reported that when she felt unwell, she usually just went to lie down for a while, (only) after she finished

the household tasks. Thus, diets might never be her priority in controlling her hypertension. Meanwhile Pak Gatot, as the other family member identified with both hypertension and diabetes, also acknowledged that modifying diet is an important intervention for his condition, but he never complained to his wife about the foods she cooked. During one of my visits, Bu Lely told me her husband usually eats less rice than the other members, as a control for his blood sugar, but he adds the foods she cooks for the family. On that day, Pak Gatot came from the mosque and he brought *soto* (traditional Indonesian soup) that had been given to him by his friend. He gave it to Bu Lely, and she said, he would not eat it, because he only eats her foods. I interpret this situation as showing that Bu Lely has total control over foods in the family, and the other family members apparently do not get involved in meal preparations. Similar to Pak Jono, Pak Gatot's family are from a Javanese ethnic background. In a Javanese family there is a clear sexual division of responsibilities. The women's main role is in the kitchen providing foods for the family. As (Geertz, 1989) illustrates, Javanese men would never do the household work, such as cooking, and they probably could not survive if they had to live on their own.

In Pak Jono's family the members were directly involved in meal preparation, thus their support in hypertension control can be observed. In Pak Gatot's family Bu Lely was the patient who had the controlling role in meal preparations; there was no involvement of family members in terms of meals preparation. The son, Kamo, was usually the first family member to assist Bu Lely and Pak Gatot to manage their conditions, although he admitted his parents never had severe symptoms related to hypertension. Therefore, he did not worry too much about his parents' health. He was actually more concerned about their safety when they had to go to the health facilities; therefore, the support he provided for them mostly involved transport to and from health facilities such as clinic or hospital.

From the illustration of Pak Jono's family, we can see he might have the motivation to modify their diets, because they were aware of the impact of unhealthy diets on their blood pressure, but he was unlikely to take any action because the family food controller was his

wife. Support for this view was when he 'ordered' a reduction of salt levels in the vegetables; sometimes Bu Karti acquiesced, but as the member of family with the central position, she governed the 'togetherness' of the family and had the power to direct the other family members. Even though the family members were aware the importance of diet modification in hypertension control, effective control over foods can be the most difficult issue in chronic disease management (Beverly et al., 2006). Social aspects of family life are known to make a huge impact on dietary control in the family setting during the management of chronic conditions (Beverly et al., 2006, Choi, 2009, Gallant, 2003). The control over foods preparation practices has been observed as a fluid process within the family settings; as O'Connell and Brannen (2013) suggested, food is embedded in power relationships and power negotiations for foods are common in a family's daily life.

The family may not intentionally undermine attempts at hypertension management, but they have to compromise the power relations within the family. Beckman-Brindley and Tavormina (1978) argued that power and interactions are dynamic among the family members, therefore there is no dominant person that exert more power than the other within a single family or across families. Dominant power is nonexistence because power in family is as dynamic as the interactions between the members, and there is no dominant person within a single family or across family because power exist in characteristic of relationship not in personal traits (Beckman-Brindley and Tavormina, 1978). This argument may apply to Pak Jono's family, in which Bu Karti may have the strongest control over foods preparation but it is negotiated. Sometimes she cooked what her husband asked for but at other times she ignored him and cooked the way she usually did; although her control behaviour would change from time to time, depending on the condition of her husband's health. Her control over foods seemed like a string, she would pull the string when her husband was feeling fine, but would loosen her grip when Pak Jono needed his health friendly foods.

Meanwhile, in other families, even though the patient occupied the central position such as Bu Lely, who always cooked for the family, modifying diets was not the top priority either.

Several aspects may influence Bu Lely's lack of motivation regarding health-focused diets; especially her perception that she managed her condition without any need to modify her or others' diets. It is quite possible she subordinated her needs for hypertension-friendly diets, due to the other family members' needs and interests. In addition, the other family members did not get involved in meals preparation, and only occasionally assisted Bu Lely, if she asked them to help or she felt unwell.

Both families are examples of the extended model; the couple live with their adult children and grandchildren. The motivation in controlling hypertension is strongly influenced by the other family members. There are also data from nuclear families that consist of elderly couples without any other family members living with them. The families of Pak Sadu and Pak Hadi are examples of such situations. Both couples are affected by chronic conditions: a) Pak Hadi and Bu Tari are both identified with hypertension, while b) Pak Sadu has hypertension and his wife, Bu Marni, has type 2 diabetes. The main differences between nuclear and extended families are discussed in this section. In extended families, the family members strongly influenced the hypertension control, especially regarding the issue of appropriate foods. Meanwhile in nuclear families involving two people, the couples have more freedom and more motivation to control their blood pressure and offer each other mutual support. For example, during the interview Pak Sadu and Bu Marni, explained how they had previously ignored their disease management, such as taking the medications irregularly, and how their social network strongly influenced their decisions regarding their conditions. Their friends suggested they should ignore the medications because of the possible side effects. However, since this couple joined the elderly group at the clinic they have radically changed their views about medication and treatment:

"Maybe you think if I don't take the medication, but I am sorry to admit, I only started taking the medication since I attended that (the weekly activity). I never took medications before." (Pak Sadu)

"Rarely". (Bu Marni)

"Some people said '(you) don't need to (take medications regularly)' I was sometimes influenced by that idea." (Pak Sadu)

"If you take medication continuously (effects) the kidneys, heart, they said, finally (he) didn't take it regularly, so the same, I didn't take (medications) regularly." (Bu Mami)
"But after I joined this (the weekly activity) in January, I now take my medication regularly" (Pak Sadu)

The couple were very supportive of each other, attending the weekly activities together, and sometimes going for exercise in the park together. They have the principle that they cannot have more than one disease, so they have to control their current conditions properly. The following interview showed they worked together to maintain their conditions and inform each other to be more aware of their health status:

"The doctor said 'it's good that your blood pressure is low, don't let it get high, don't let your cholesterol get high, it's enough to have one illness' he said 'if you can't have normal condition, then one illness is enough', that why I take care of it, he (Pak Sadu) has hypertension, I have diabetes, I do my best to prevent my cholesterol from getting higher. I control his foods, I told him not to eat too much meat, and always tell him to control his emotions (Bu Mami)
We reduced the meat, mostly chicken, I think it's ok, since we joined the weekly activity fries have been cut, we prefer steamed foods" (Pak Sadu)

From the excerpts above, it can be seen the couple was challenged by their social network, such as friends. But the couple then attended the elderly group at the clinic and decided to change their behaviour after that. The weekly activity they attend consists of several sessions that are not always performed every week. For example, in the first week of the month, the group members will have a blood sugar check, blood pressure check, medications, weight measurement, exercise, health education and singing session. For the other weeks, they only have exercise sessions and blood pressure checks. The session changes will depend on the availability of the staff. Pak Sadu and Bu Mami admitted that they had gained more knowledge about their conditions and the consequences if they left them untreated. They understood that a stroke is the price they have to pay for not taking the medications regularly, as they had first-hand experience of caring for Pak Sadu's late father, who died after having a stroke. For them, even though they do not have any symptoms, maintaining normal blood pressure by taking medication regularly, as well exercising, are now priorities.

Similar to Pak Sadu's family, Pak Hadi and Bu Tari, were also committed to attending the weekly activities at the clinic, and they did not have such a strong influence from the family members that prevented them from controlling their blood pressure. Bu Tari sometimes cooked for both of them and she was aware of the foods that were suitable for their conditions. Even though when she bought the foods from food sellers, she would choose foods that were healthy enough for them. However, care this might be the result of her background as a midwife, and also one of her relatives is a physician. This couple were evidently aware that their condition required them to properly control their hypertension in order to prevent it causing a stroke, as they said during the interview:

"The most worrying is stroke, (h), that's why we do the prevention by taking medication, we have regular check up every 6 months for the renal function and so on, and then the diets, to prevent the impact, because we are scared of stroke. (Bu Tari)

For me the treatment as I said earlier, I consult the clinic, and the physician at hospital, I was given medications, so as the physician said being identified with hypertension means taking medication for the rest of your life. So, I was given hypertension medications in addition to other supplements. If I had other symptoms, would also be given such as purin and others. So, for me, especially, since I was diagnosed with hypertension every month I went to X Hospital, for an examination and others, and then every month I am given the same medications because I don't have other symptoms" (Pak Hadi)

The couple sometimes drink a potion too, made of bay leaves, one of them usually boiled the bay leaves for both of them. They knew about this potion's recipe from the clinic, and they still consume it sometimes when they have the time to make the potion. They also tried to use other leaves such as soursop. Both plants were believed help to decrease blood pressure. The couple implemented the information they received from the clinic. From the interview it can be clearly seen that they support each other, even though they did not show any symptoms. Their conduct was motivated by their awareness that hypertension control is very important to prevent stroke.

Both types of family, the extended and nuclear family, felt the severity of hypertension, especially the incidence of stroke caused by it. In an extended family

the members were more likely to support the patients when they complained about their hypertensive symptoms. However, in the examples of nuclear family the couples were more mutually supportive, although they had never shown any symptoms of their illnesses. The extended family, with more family members than in a nuclear model, has more needs and interests to be met, resulting in various negotiations regarding such issues as hypertension control. A nuclear family, on the other hand, experiences far fewer negotiations because the couples have similar goals in preventing the impact of their illness. Together the similar goals and adequate information related to illness management foster collaboration, mutuality and meaning making, that are very important contributors to disease management (Houston-Barrett and Wilson, 2014).

5.6.1 Summary

In a family as a system, hypertension and its least wanted impact, a stroke, would be expected to cause the family members to support the patients in controlling their hypertension. The family members had the intention to provide support, but there were variation between the extended families and nuclear families. In an extended family, the presence and absence of symptoms strongly influenced the quality and quantity of hypertension support offered by family members. The presence of symptoms elicits family members' support for the patients. Meanwhile, in nuclear families, where both the husbands and wives had been identified with chronic conditions, they had similar goals regarding their condition management. Thus collaboration in controlling hypertension was mostly observed as happening in the nuclear family even though there were no symptoms in evidence.

5.7 Chapter summary

In this chapter I examined the contextual and conceptual elements that this research found to have mediated hypertension control within family settings in the city of Denpasar, Bali, Indonesia. For the contextual aspect, this study found that

hypertension control was predominantly influenced by other family members, thus creating a dynamic control model mediated by the following considerations: a) roles and responsibilities, b) economics, c) stress and coping, and d) the presence and/or absence of hypertensive symptoms. Patients' roles and responsibilities may both restrict and encourage such patients to engage in hypertension control, especially by engaging in physical activities. Similarly with economic conditions, the hypertension control was potentially compromised when the patient is without adequate funds, creating an inability to buy appropriate foods. Equally, adequate funding can cause problems if a diet contains a surfeit of animal proteins or animal fats. It is fair to conclude that a person's finances strongly influence their diet choices. Additionally, stress experienced by family members plays an important part in hypertension control within the family setting. Families create the dynamics of hypertension control due to other members causing or being stressors or help patients to manage their stress. Another important element found in this study that influenced the hypertension control within the family setting was the presence and/or absence of the patients' hypertensive symptoms. The presence of symptoms increased the intention of family members to support the patients in controlling their blood pressure. However, in the absence of symptoms, family members were unlikely engage with and support the patients, because they perceived that the patients should take responsibility for their condition. The appearance of symptoms motivates the family members to engage in hypertension control due to the threat of hypertension's advanced impact, especially stroke.

In term of conceptual aspects, the above four elements that this research found to have mediated the hypertension control within families in Denpasar, were embedded in the system principles: 1) equifinality (families' efforts to make adjustments in order to achieve a steady state), 2) wholeness (all elements that are interrelated, interconnected and interdependent within families) and 3) feedback (so

enabling a family to function as a self-controlling system due to its information exchange ability). Furthermore, individuals' power and freedom play a role in the construction of those three elements which later influence the implementation of hypertension control, both through pharmacological and non-pharmacological approaches within family setting in Denpasar. Those three elements within a system have contributed as double edged-swords, which could either compromise and/or encourage the implementation of hypertension control.

The following section is a discussion chapter, which discusses interpretations, opinions, and effects of the key findings relating to hypertension control within a family context in Bali, Indonesia.

6 Discussion

6.1 Introduction

The aim of this thesis was to understand family's experiences in hypertension control in Denpasar, Bali, Indonesia. The study was informed by a focused ethnography approach that enabled me to observe realities and understand the construction of those realities in a family's everyday life (Holstein and Gubrium, 2008) without being intrusive to the families themselves (Daly, 2007). Focused ethnography enabled me to gather considerable amounts of data from eleven families in Denpasar through interviewing and observation. The contextually rich data I collected allowed me to build a theme and a conceptual framework of hypertension control in Denpasar, in order to address the research questions raised in this study:

1. In what ways do family members experience the impact of an individual living with hypertension within a family group?
2. How do family members experience the management of an individual's hypertension control within the family group?
3. What are the potential facilitators for, and barriers to, hypertension management in families?

I have made the decision to utilise general system theory (Von Bertalanffy, 1973), agency concepts (Giddens, 1986), and protection motivation theory by Rogers (1975, 1983) to interpret the study findings regarding families' experiences in daily hypertension control in the context of Denpasar. Developed from the findings set out in Chapter 5, in this chapter I set out to elaborate the key elements identified through the analysis process. The conceptual framework in chapter 5 (section 5.2, page 212) sets out the family as a dynamic system in hypertension control. The dynamics of that control were influenced by four elements: 1) roles and

responsibilities, 2) the economics, 3) stress and coping process, and 4) the presence and absence of the symptoms, embedded in the principles of system theory: the concepts of equifinality, wholeness and feedback. This chapter discusses important insights related to the study's findings that are relevant to existing literature concerning hypertension control.

Previous studies have suggested that family is basically a static milieu that will always increase individuals' motivation to adopt healthier behaviour and maintain positive health once such decisions have been made (Kelder et al., 2015, Shor et al., 2013). Furthermore the family is portrayed by the patients and family members as the closest support available for the patients; therefore, the members are always available when the patients need access to them (Fort et al., 2013, Magrin et al., 2015). However, this study found that a family is a dynamic system in hypertension management, with some elements of the system either facilitating or preventing hypertension control.

It was evident in my data that the family as a system strongly influenced the daily hypertension control among patients in Denpasar. This chapter discusses important elements contributing to this main finding, as well as the importance of this finding to improving hypertension control in Indonesian context. The following sections discuss: 1) family as a system in hypertension management, 2) cultural and religious activities' impact on hypertension control, 3) family participation in hypertension control, and 4) the importance of family in hypertension control

6.2 Family as a system in hypertension management

Family can be seen as an open system that self-regulates in order to try to maintain a so-called steady state based upon dynamic interaction (Bockus, 1975). Family as a system reacts to input by feedback processes. This feedback can be positive, thereby increasing the change overtime, or a negative feedback process

that maintains stability and prevents changes (Bavelas and Segal, 1982). In hypertension control the feedback aims to prevent further organ damage resulting from uncontrolled hypertension. In this study hypertension management was consistent with feedback loops in system theory. For instance section 5.6 (page 287) explains that the majority of family members, from all families, worried if the hypertension would cause a stroke, because stroke is perceived as a severe condition that could potentially increase the families' burdens due to the disabilities a stroke may cause. Therefore, by keeping the blood pressure low in order to maintain the patient's stability to prevent a stroke, family members would take action to provide support for the patients when they complaining of, or showing, hypertensive symptoms. For example, family members provided low stress situations in their homes to minimise the patient's symptoms, or meals that they believed reduced the blood pressure. Moreover, the family members also supported the patients in taking their medication; for example, by placing the medication in a reachable place so the patients could take it regularly. The patients' responses to such feedback actions were evident in taking their medication regularly, and feeling less stressed. Those changes that the family members made are in the form of negative feedback, because they wanted to improve the patients' health status, or to maintain the patients' blood pressure within a normal range, in order to prevent the development of any unwanted conditions such as a stroke.

Meanwhile some family members did not make any response to hypertension, leaving the hypertension uncontrolled and potentially able to cause further organ damage; this is a a form of positive feedback. For example some family members encouraged the patients to avoid taking medication, because it caused unwanted side effect (section 4.3.10.2, page 203, Pak Kanda's family). Another example of positive feedback was the family members who perceived hypertension as not being a life threatening condition. Such a perception resulted in no special actions to

manage the member's hypertension, so keeping the situation in the house the way it was. Similarly for diets, the majority of the families kept to their regular diets, instead of providing low salt and fat diets for the patients. The main reason for the unaltered diets was because the children's wishes were the priority and so preparing their favourite foods maintained the steady state. These actions potentially prevented the patients from taking their medication, nor could they reduce the amount of salt or fat in their foods; there were no alternative proactive interventions offered by the family members. These situation leave the member's hypertension uncontrolled, and can lead to other organ damage as well as changes in the patients' health status due to the development of other chronic conditions, such as kidney and heart problems.

Positive and negative feedback may not have value in terms of communication and interaction because those feedbacks are the way families maintain their *status quo* overtime (Bavelas and Segal, 1982). However, in terms of hypertension control, both types of feedback are potential barriers providing support which, in turn, may increase and/or decrease the incidence of an advanced impact of hypertension such as stroke, kidney disease or heart disease. Ashida (2012) reveals that adults who were quite willing to try to change their health behaviour often failed to do so because their family were unlikely to support them. Various factors influence family members' support to other members identified with certain medical or other negative conditions. These factors include: 1) their knowledge about the disease, 2) financial, culture, and 3) the disease symptoms (Horowitz et al., 2004, Dumont et al., 2008, Aschbrenner et al., 2012). In addition to those factors, the the lack of support from other family members can be because a family, as a goal-seeking system, has priorities that may be more prominent in maintaining stability.

As a goal seeking system, family has the ability to accomplish the same goal through different routes; this characteristic in system theory is known as equifinality (Von Bertalanffy, 1973). This current study found families sometimes compromising

their hypertension control because the family had to follow an alternative route to accomplish their goals. For example, a patient from an extended family, who was living with their adult children and grand children. The adult children have goals fulfilling the needs of their family, and they have to work and earn in order to achieve those goals. Women also go into the workforce, whilst at the same time having to raise their young children; so their alternative path to accomplish their goals was utilising assistance from other family members, mainly from their parents or the patients. Based on this current study's findings, taking care of grandchildren at some point can be very demanding for the patients, often increasing their stress levels; as experienced by Pak Hendra (in section 5.3.1.1, page 223). It is now well established that stress is strongly related to increases in blood pressure (Wright et al., 2014). As a complex interactive system the family strives to accomplish its goals, but this effort has implications for the patients' wellbeing by causing stress, and subsequently compromising their hypertension control.

In an Indonesian context, where intergenerational living arrangements are common, grandparents providing childcare for their grandchildren is a duty. This role is seen as a form of investment for the future, based on the expectation they in turn will be taken care of by their children and grandchildren in the future (Snopkowski and Sear, 2015, Schröder-Butterfill, 2004). However, this important type of relationship between grandparents and grandchildren is mostly overlooked because it is seen as a life circle that normally occurred in every family. On the other hand, some grandparents raising grandchildren actually experience significant levels of unhappiness and stress (Strawbridge et al., 1997, McLaughlin et al., 2017, Lumpkin, 2008, Doley et al., 2015, Coall and Hertwig, 2010). Similarly, this study found childcare provision by the grandparents as an important stressor that potentially impacted their hypertension in a harmful way. Even though providing the care caused them stress, that caring is a societal norm that they are expected to carry

out. Taking care of the grandchildren is an investment for the elderly's future. The perception that grandparents provide childcare as an investment for their futures is probably related to the poor standards of social security for the elderly in Indonesia and other similarly structured societies. Thus, they have to ensure that their offspring will take care of them in their old age because nobody will provide security for them other than their family. However, this interdependence within a family at times appeared to compromise the elderly's health. Further research may be needed to evaluate the elderly's well-being within intergenerational living arrangements. Particular focus should be directed towards the issue of childcare provision by the grandparents, so relevant policies to improve the elderly's well-being may be developed in anticipation of the increased numbers of the elderly population, as people live longer.

Research about hypertensive patients in an Indonesian setting has mainly focused on whether the family provides support for the patients; the participants in those studies being in most cases the patients or the primary carer (Abikusno and Kusumaratna, 1998, Rahmawati and Bajorek, 2017). Abikusno and Kusumaratna (1998) studied the characteristics of individuals who participated in an elders' club in a health centre in Jakarta. A main finding was that the elderly who were identified with chronic diseases, such as hypertension, obtained support from their adult children. However, there were no clear explanations regarding what kind of support, nor the way support was provided. Rahmawati and Bajorek (2017) conducted research in Jogjakarta, Central Java, where they found that family members supported the elderly in managing their conditions. However, again it was unclear what kind of support was provided for them. The majority of studies in Indonesian settings were conducted as surveys (Hussain et al., 2016, Sohn, 2015, Widjaja et al., 2013, Christiani et al., 2015, Kisjanto et al., 2005), a research situation which leaves any understanding of the family as a unit of care unclear. Therefore, those

studies may capture only partial images of hypertension management in daily life. Meanwhile this current study captured broader aspects of family life and found family as a system to have dynamically influenced hypertension management. Not only do the members provide support but also they can and do challenge the hypertension control programmes in place. If hypertension control programme development is only based on or informed by quantitative studies, or studies that only capture the patients' perspectives, then the most significant element that potentially influences hypertension management - the family - has been ignored.

Family is part of a social collective that is culturally bound (Parsons, 2014). Culture provides norms for behaviour and thus influences the roles and power within a family (Johnson, 2013). Due to the importance of culture in family life, the following section discusses culture in relation to hypertension control, informed by the findings presented in chapter 5.

6.3 Cultural and religious activities' impact on hypertension control

Each ethnic group in Indonesia has its own culture as their identity, and they preserve their culture to improve the position of their ethnic group within the multi-ethnicity of the Indonesian nation (Picard et al., 1997). The family system introduces individuals to cultures, values, and customs that are practiced within society; through those experiences the adult children gain the required understanding, emotional equipment and moral commitment to act as members of both their own community, and society in general (Geertz, 1989). In Indonesian society religion and culture cannot be separated, because the expression of religion is embodied in culture (Geertz, 1973). The cultural and religious activities in Indonesian society mostly include family as a part of the wider social network. Social interactions in Indonesia are collective, consensual and cooperative (Bowen, 1986). The most

important key term to describe the social interaction related to this study's finding is *gotong royong* or 'mutual assistance'; a behaviour that is adopted across the country under various names (section 5.3.2, page 231). The *gotong royong* is also affiliated with religious and cultural activities. For example, in Bali, the *gotong royong* element in religious activities is called as *ngayah*. Based on this current study, patients' involvement in *ngayah* caused them to compromise their hypertension control behaviour, such as abandoning physical exercise, as experienced by Bu Siwi (see section 5.3.2.2, page 241). This discussion focuses on Balinese society because it was so prominent in challenging the continuity of hypertension control, especially for women.

Balinese women with Hinduism backgrounds, still mainly perform duties around the sphere of the home (Goodlander, 2012). Within the family, women have primary roles to foster balance and harmony; they are expected to marry, produce children and 'work as part of family team' (Suryani, 2004, p.213). However, as a part of the family team, the tasks and duties within the family are never equal; women are expected to perform more work and duties than the men. Susilo (2003) suggests Balinese women start their day before dawn; they go to traditional market for groceries, they work all day preparing meals, minding children, and are often still awake until late preparing offerings for different ceremonies.

Their lives become even more hectic if they also have to enter the work force as the second provider for the family. For retired elderly women, they might not go out to paid work anymore but they will take on another duty providing childcare for the grandchildren, as mentioned in the previous section. Yet, as well as their grandchild caring duties those grandmothers will still be taking part in religious and cultural activities. Balinese women's hectic lives were also observed during participant recruitment, in the early stage of this study. I found it was more difficult to reach female than male patients. The main reason female patients were reluctant to

take part in this study was because they were so busy with their religious activities, although they still managed to attend the weekly activities such as having regular check-ups and physical activity sessions at Puskesmas, no matter how busy their life was. Consequently, for the recruitment process I finally managed to include only three female patients, who were all very eager to attend the weekly activities at Puskesmas and seemed very committed to their hypertension control. Two of them were not only engaged in Puskesmas activities but also regularly attended another exercise programme (Bu Tari in section 4.3.9, page 200) or regularly exercised at home (Bu Siwi in 4.3.11.2, page 206).

However, most of the time they had to choose between going to Puskesmas or attending the religious activities; mainly they chose the latter. Carrying out the rituals and collective work are obligations for the family, and there will be sanctions for the family if they fail to do so (Warren, 1993). Other than compromising their attendance to Puskesmas, some women sometimes had to compromise their sleep patterns due to their busy days attending religious activities. Meanwhile sleep deprivation has been strongly related to increases in blood pressures and heart rates (Pankow et al., 1997, Gangwisch et al., 2006, Calhoun and Harding, 2010, Ana et al., 2013, Lusardi et al., 1999). Primarily, women are more concerned with their health, when compared to men (Thompson et al., 2016, Galdas et al., 2005, Tenenbaum et al., 2017, Wang et al., 2013). However, based on this study's findings, cultural and religious activities exert an immense influence on the regularity of the women's hypertension management behaviour.

This study's findings show cultural practices also affect hypertension control, especially diets. The majority of cultural and religious practices within Indonesian society involve various traditional meals. In Balinese society, at every cultural and religious event, food is a crucial part of that event. In religious events different foods are part of the offerings, and sometimes will be shared with the attendees as a

blessing. Similarly during special occasions such as weddings, foods are a fundamental aspect of the celebration. During the reception guests enjoy various traditional foods that mostly contain meat, especially pork. This study found that patients who were continuously attending such gatherings complained their blood pressure increased 'after the event'; yet that did not inhibit them from continuing to attend.

Meat used to be associated with social status (Ma, 2015, Kinaston et al., 2013, van Overveld et al., 2018). People from a higher social status would show their wealth and purchasing capacity through foodstuffs; the more they consumed foods from animal sources that were rich in protein, the more affluent they were judged to be (Ma, 2015, Kinaston, et al., 2013, Palma et al. (2017). In this modern life, due to increased incomes, different foods become more affordable, and now all social classes can easily afford meat and other foods rich in protein (Seaman, 2013). However, even though meat is more affordable, a plentiful supply does not change the value of meat from being a luxury food. Meat, especially with high fat content, has always been relished and is perceived as a luxury food; therefore such meat is primarily, even exclusively, served for special occasions; notably feasts in South East Asia (Hayden, 2003). Meanwhile, in Balinese society, an individual may celebrate many festive days, or attend many receptions, depending on the number of social organisations they are involved in, or the number of relatives in their extended family. Subsequently, an individual can potentially eat meat, especially pork, frequently. Pak Sadu (see section 5.3.2.1, page 233) said that the traditional food made of pork was the one he and the family really enjoyed; there was no question it was the 'most wanted' dish when attended special occasions, such as wedding receptions. Also it should be pointed out that foods rich in fat and protein, especially of animal origin, have been associated with various chronic diseases such as cardiovascular problems, cancer, and diabetes (Schulze et al., 2018, Anand

et al., 2015, Chiu et al., 2016, Hallström et al., 2015, Kahan and Cheskin, 2014, O'Neill, 2015).

This study shows that culture is a very important determinant in hypertension management. It demonstrates how health-care outcomes are attributable to factors that are beyond the control of care nurses. Culture cannot be ignored in healthcare, which means it is crucial to understand the influence of culture on a person's health and well-being. The increasing diversity of patients from various cultural background challenges the health care nurses to provide culturally competent services (Ihara, 2004). However, being competent about one's own culture is a priority in order to differentiate between other cultural values (Ihara, 2014). Similarly, in this study health-care nurses should have recognised the impact of cultural practices on hypertension, in order to prevent a patient's health deteriorating due to their engagement in religious and cultural events. As the majority of patients and health care nurses come from a similar cultural background, it is therefore crucial for the health care nurses to understand and make critical judgments about their own culture, which they share with their patients.

Culture and religion are potential barriers in hypertension management, especially for Balinese patients. In addition, family as system also posed barriers to individuals' hypertension management, although family also support the individual to manage their condition. The following section discusses family participation in hypertension control in an Indonesian context.

6.4 Family participation in hypertension control in Indonesian context

This study found that diet is the most important element of hypertension control as far as family participation is concerned. The other aspects that family also participate in are: a) stress management, b) physical exercise, and c) medication. However, even though family members participated in those aspects, the

participation that actively controlled hypertension is not a continuous process. This research revealed the family as a dynamic system in the management of hypertension. Based on this study the family mainly participated in hypertension management when the patient's symptoms appeared; however, when those symptoms were absent, family members were unlikely to take any actions for hypertension management. When symptoms appeared the members' participation mainly involved the changing of diets and maintaining a conducive, relatively stress-free environment for the patients. For example, Bu Karti, Pak Jono's wife, (see section 5.6, page 292) said when her husband complained about his increasing blood pressure, she immediately cooked more vegetables for him, with the hope such ingredients would help him to reduce his blood pressure. Another example of hypertension management was family members started creating calm and conducive environments when their father or grandfather became upset or felt annoyed; initiatives to soothe the patient's negative emotions. Meanwhile for physical exercise nuclear families that consisted of couples were more likely to participate in physical exercise activities than were the patients who lived in extended families. For example, in Hadi's, Joko's Sadu's, and Dago's families, husbands and wives were involved in the same physical activities, encouraging each other, or actively assisted their spouse to do their exercising. As for medication, the family members mostly acted as reminders for the patient to take their medication regularly, as well as offering financial support to meet the expense purchasing the medicines.

In the absence of symptoms, hypertension is not considered as threatening by either patients or family members. For example a family member said her husband is always in good condition, therefore diet modifications and reducing salt would not change anything (section 5.6, page 290). Hypertension is known as a 'silent killer' due to majority of those afflicted with the condition are unaware, even

though their blood pressure has increased (Bell, 2015). Even though patients have been identified with hypertension, it is mostly perceived as an intermittent symptomatic condition, instead of a chronic symptomatic condition that needs long term control (Meyer, 1985, Sharkness, 1992, Ogena, 2018). Meanwhile, poor hypertension control has been related to higher drug bills, more physicians visits, and the increased prevalence of heart disease and stroke (Paramore et al., 2001, Reach et al., 2015, Ogena and Burnier, 2018).

Family members perceived medication to be the most important element in hypertension control; other non-pharmacological interventions were perceived as much less important for hypertension management, even though some interventions such as low fat diets, less salty diets, and less stress were acknowledged as helpful. Most patients and family members rely on medication for hypertension management, and perceived other interventions as offering only minimal contributions to blood pressure reduction (section 5.6, page 290). Meanwhile, non-pharmacological interventions, such as changing their regular diet into a vegan diet, helped participants from African Americans background to significantly lower their systolic blood pressure (SBP) by 1.3 mmHg and their diastolic blood pressure (DBP) by 0.6 MmHg, when compared to those participants on omnivorous diets (Fraser et al., 2014). Moreover in a salt reduction initiative, reducing salt intake to 6 g/day is associated with lower SBP/DBP of 7/4 mmHg among people with hypertension, and 4/2 mmHg among those without hypertension (DiNicolantonio and Lucan, 2014). Three months regular physical exercise reduced the SBP by 5 mmHg and DBP by 3 mmHg among older adults (Herrod et al., 2018). Additionally, the lower blood pressure levels remained stable if the exercise was continued to 6 months (Farinatti et al., 2016). Non-pharmacological initiatives can include: 1) reducing weight, 2) adding more fruit and vegetables to daily diets, 3) taking regular exercise, 4) quitting smoking, 5) reducing alcohol consumption and 6) developing stress management

skills and strategies. These initiatives have been highly recommended for use against stage 1 hypertension and later stage hypertension, as complementary initiatives to antihypertensive drugs, because such initiatives have shown valid results in reducing blood pressure which are as effective as medication (Appel et al., 1997, Li et al., 2014b, Svetkey Lp and et al., 1999, Moran et al., 2015, Miller et al., 2002).

Hypertension guidelines encourage self-management due to its cost effectiveness and effectively reducing high blood pressure. However, its implementation is strongly influenced by the relationship of individuals within the patient's family (Narain, 2011, Whitehead et al., 2018)(Narain, 2011, Whitehead et al., 2018). Individuals do not live in isolated environments, but they are interrelated, interdependent and interconnected with the family; thus a family is the key to constructing an environment that is conducive to the implementation of self-management (Whitehead et al., 2018, Rosland et al., 2010). For example, this current study found patients acknowledged non-pharmacology interventions are, or can be, important for hypertension control. However, patients only proceeded to take an initiative, especially diet modification, when they experienced hypertensive symptoms, or their blood pressure increased. The priority in the family only changed slowly over the time. If families could commit to take part in diet preparation, where they can exert the greatest influence on this aspect of hypertension management, then the prevalence of the traumatic impact of uncontrolled hypertension, as in stroke and debilitating cardiovascular disease, may begin to decline.

In an Indonesian context, the patients' families were unlikely to be considered in chronic condition management; the health education that take place, perhaps incidentally, in consultation rooms is mainly targeting individuals (Ministry of Health Republic of Indonesia, 2013). This one-to-one paradigm exists despite the fact that an individual is a part of a family, in which he/she is interconnected,

interdependent and interrelated with other family members, wider social networks, and the external environment. Individuals influence, and are influenced by, other family members.

No health interventions were designed to include other family members in hypertension control, until in 2016 the Indonesian government, through the Ministry of Health, issued Regulation 39, which covers the implementation of the 'Healthy Indonesia Programme' through a family approach (Ministry of Health Republic of Indonesia, 2016a) (section 2.3.4.3, page 50). The new regulation suggests interventions that encourage families to take part in chronic disease management. Guidelines were created for healthcare nurses to conduct: 1) regular home visits, 2) giving information, 3) conducting focused group discussion, 4) counselling, and 5) various community meetings to address issues related to disease management. The new regulation also set indicators to mark a family's health status. A family with one or more of its members identified with hypertension will be categorised as healthy if the patients are taking medication regularly, and are not smokers. These two indicators are important to diagnose whether hypertension has been controlled or not, based on the new guidelines.

However, the new guidelines set just two indicators for assessing if families with hypertension are healthy or not; which seems a very vague specification. Based on this study, issues around diets, physical exercise and stress management, in addition to medication and smoking, were also prominent. Furthermore the guideline shows family assessment based only on a score, without including any qualitative data to obtain a more comprehensive picture about the family, its composition and behaviour. Scoring based on a quantitative assessment approach is unable to provide detailed descriptions of: 1) situations, 2) events, 3) people, 4) family members' interactions, 5) their behaviour, and 6) relationships with wider social systems. Whereas, based on this study, various situations due to family members'

interconnectedness, interdependence and interrelationships have influenced the hypertension control through both pharmacological and non-pharmacological interventions.

Family as an open system is self-regulated, reacting to input via a feedback process. This study found the hypertension management in daily life among families in Denpasar is consistent with the feedback loop in system theory. Family members may exert positive and negative feedback both to improve and prevent the implementation of hypertension management within their family settings. Furthermore, as a goal seeking system family has the ability to accomplish a goal through different routes that consequently mobilise the members to take different roles and responsibilities within their family. Different roles and responsibilities resulting from the goal seeking principle within 'family as a system' compromised the hypertension management, which subsequently impacted the patients' health. Additionally cultural and religious practices are potential barriers to effective hypertension management. Some practices of culture and religion strongly influenced both diets and sleep. Various aspects related to patients' interrelationships, interconnectedness and interdependence are potential barriers to efficient hypertension management. However, hypertension as an asymptomatic condition is mostly perceived as an intermittent symptomatic condition, rather than a chronic symptomatic condition that requires long term control. In addition, the families in this study perceived non-pharmacological interventions as relatively unimportant, thus mostly relying on medication treatment alone for their member's hypertension.

I found that individuals frequently lacked any influence over controlling their blood pressure, whereas the family members exerted a strong influence over any hypertension management that occurred. Therefore I argue for the importance of considering the 'family as a system' approach in health promotion and disease

prevention, specifically for hypertension reduction, instead of relying on the biomedical, drug-based, non-holistic approach that focuses only on the individual patient.

7 Recommendations

This study explored the family's experiences in hypertension control in Denpasar City, Bali, Indonesia. The results were informed by the family as a dynamic system in hypertension control within an Indonesian context. Four influencing factors were in evidence: 1) the roles and responsibilities, 2) economics, 3) stress and coping, and 4) the appearance and absence of symptoms. These four factors are embedded in system principles including a) equifinality, b) wholeness and c) feedback. With this research-based evidence recommendations, especially for areas of practice and research, are needed to develop better initiatives that can accommodate the 'family as a system' concepts that are relevant to hypertension management. The recommendations for practices are broken into institutional and patient-nurse levels. Recommendations for the institutional level are important because policies and national implications of this research can trickle down to not only affect behaviour at the patient-nurse level, also influence hypertension management outcomes. The following sections discuss recommendations for practice and research.

7.1 Recommendations for improvements of hypertension management in practice

Hypertension management practices in Indonesia's setting mainly target individuals to encourage patients' self-management (Ministry of Health Republic of Indonesia, 2013). However, hypertension control remains sub-optimal due to individual factors challenging the programme (Rahman et al., 2015b). The individual factors have always been assumed purely from the individual *per se* (Peltzer and Pengpid, 2018, Rahman et al., 2015b). However, this study found the family to be a very important factor influencing the hypertension control at the individual level.

Family involvement in discussions, planning and implementation of health services for their family members who had been identified with hypertension will improve the family's support. That support will eventually improve the hypertension management outcomes. It is important for health care organisations that set up avenues for nurses to understand family perspectives regarding self-management of hypertension, to help in developing family-focused, health-service innovations. The following section discusses the recommendation for institutional level, followed by patient-nurse level.

7.1.1 Institutional level

The contribution of this focused ethnographic study to the public health and health care institutions that serve communities within Indonesia is to provide rich data about the experiences, practices, barriers and facilitator for hypertension control in the family. In order to improve health from within a family, it is important for health care organisations to acknowledge that power is dynamic within the family (Beckman-Brindley and Tavomina, 1978), and the family is part of a social collective that is culturally bound (Parson, 2014). This study shows the individual approach alone in hypertension management does not fit into an Indonesian context. Caring for individuals in an Indonesian setting, means those involved are interrelated, interconnected and interdependent with other family members, the external environment and the wider social network. In order to improve hypertension control outcome a greater effort is needed to engage families in hypertension control that will potentially increase their support in helping the patients to control their blood pressure.

Institutions should critically reflect upon health promotion theories that have been adopted for hypertension management, as the majority of such theories focus on the individual level, such as the theory of health belief model, and the theory of

planned behaviour, trans-theoretical model (Smith et al., 2011, Pickett et al., 2014, Li et al., 2008, Pedersen et al., 2015, Taylor et al., 2006a, Mohammadnezhad et al., 2015, Mahomed et al., 2008) . Institution should start to adopt family theories in creating intervention for hypertension management, as well as to help nurses to shift their mind set, so allowing those nurses to accept that hypertension is strongly influenced by the dynamics of the family as a system.

A family's priorities, and different perceptions about hypertension, are challenging when they are to be included in hypertension control. As a complex system, a family will face various issues that cause hypertension to be far from a priority. In particular hypertension, as an asymptomatic disease, renders it unlikely to be a daily life priority unless the patient raises a complaint about their condition. As an open system, families exchange information, materials and energy with their environment (Friedman, 2003). The open families welcome ideas and information to resolve their problems (Kantor et al., 2000). From this study the family members' perceptions about hypertension were developed due to information they received from friends or social media, which was not always reliable. The information received is later shared and believed by the other family members. If hypertension control interventions are not considered as important, this could be because the family members have different perceptions about hypertension. In such a case it would be important to update their knowledge about hypertension disease and its implications.

Institutions can assist nurses in creating hypertension management programmes that involve family members in patients' health care, improving assessment guidelines with a focus on obtaining information about the whole family, not only individuals. It would also be to create innovative interventions to educate and encourage family members to take part in their patients' health care. With more programmes focusing on family involvement, families would gain better knowledge

about hypertensive diseases and as a result could provide better support for the patients.

Cultural impact on hypertension management should also be a consideration. The hypertension control initiatives mainly ignored cultural backgrounds. In the context of Bali for example, the Balinese will spend more time on cultural and religious activities than many other ethnic groups in Indonesia. However, nurses appear unaware if such practices have significantly disrupted the implementation of hypertension control initiatives, and they tend to ignore those aspects. Their lack of awareness of culture's impact on their patients' lives may be due to lack of reflexivity as they come from similar cultural and religious backgrounds. Lack of self-awareness is one of the barriers to critical thinking (Kingsbury and Howell, 2016).

Education institutions have to equip their students with cross-cultural education as it is necessary element for future culturally competent nurses in Indonesia's health system (Institute of Medicine Committee, 2003). Providing cross-cultural education is important, but assisting the students to raise their awareness of their own culture is also important. Kingsbury and Howell (2016) suggested that thinking critically about everyday life is very important in developing such habits.

The following section discusses the recommendation for patient-nurse level practice

7.1.2 Patient-nurse level

Nurses' behaviour and attitudes help them to work and assist families to achieve their goals in hypertension control. During the assessment process, nurses have to understand the family's level of understanding about hypertension, its management and the family's position on the issue of disease management. Such

information may predict their behaviour when it comes to providing support for their patients (Macaulay et al., 2005).

As exemplified in this study, nurses may need to ask about the roles and responsibilities of the patients within the family and what that entails with regard to hypertension control. Next, a nurse can obtain information about the family's resources, especially financial, and what aspects of hypertension control may be influenced by financial issues. Another important matter the nurse should explore relates to the family's stress and coping, where family members can be both stressors and stress-reduction managers. And finally, it is important to know what motivates the family to provide care for the patients in daily life, as this relates to whether the family regularly supports controlling the individual's blood pressure or only when the patient shows hypertensive symptoms.

Practically, nurses can learn about cultural impact on hypertension control. Nurses may well miss diet control practices during the festival days. For example, one patient reported his blood pressure was getting higher almost every time after the celebratory food had been consumed. The nurse can provide information related to diets, rest and sleep during the cultural and religious events, to raise families' and patients' awareness. However, how interested the patients will be is debatable.

In addition to providing information related to hypertension and its treatment, nurses can include practical sessions for the family members, especially in preparing meals for the patients.

The following section discusses the recommendation for future research.

7.2 Recommendation for future research

This study raises question for future research in the areas of: 1) decision making in health care within intergenerational families, 2) family-related health policies development, 3) families' experiences of both biomedical and alternative

treatments, 4) cross-cultural patient-nurse experiences in community settings, 5) health interventions for family's health improvement, and 6) evaluation of the family-centred approach in chronic disease management.

The research methods in this study were used to access and gather data from families; the latter being known as a private social group. Focused ethnography is recommended for conducting family research. The approach enables the researcher to have close contact with participants without being intrusive. This study utilised interviews and observation as data collection methods and these methods adequately portray the families' lives and experiences in relation to hypertension control. For further research additional methods such as photos and videos may be considered, in order to construct a more complete picture of the family.

7.3 Summary

This study contributes to knowledge by providing the insight that hypertension control is predominantly influenced by the patient's family when the patient is based in the family home. Therefore, the current individual approach to hypertension control in Indonesia may need re-evaluation. Also the study suggests hypertension control should take into account the importance of cultural and religious aspects which may impact the initiatives' implementations.

8 Conclusion

Hypertension is a modifiable chronic disease. However, it causes more hospitalisations in Indonesia (Centre for Data and Information, 2012) than any other medical condition. Individuals identified with hypertension are part of a family that is interconnected and interdependent from other family members and the external environment. These interrelationships may or may not provide support for the individuals in controlling their blood pressure. Research was then conducted to explore families' experiences in managing hypertension control. This study was conducted in Denpasar, Bali and its main finding was that the family is a dynamic system that provides support for, but at times also prevents, the implementation of hypertension control. The dynamic of the control is influenced by roles and responsibilities, economic issues, stress and coping, and the appearance and absence of hypertensive symptoms. These aspects are embedded in system theory principles such as equifinality, feedback and wholeness. The contribution of this study includes a conceptual framework depicting the dynamics of hypertension control within family groups in Denpasar.

Based on this study 'family as a system' cannot be ignored during hypertension management programmes and attempts relating to disease management. The complex interrelationships between patients and other family members in a family unit may support or challenge hypertensive disease management, or even do both. Therefore, to include the family members in disease management is a much needed initiative to improve the current patient-focused hypertension treatment situation. However, in order to include the family members in disease management programmes it would not be enough just to give information about the do's and don't's. It would be essential to thoroughly assess the family life

and the family's dynamics, as well as providing caring skills for the family members that could be practiced every day.

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List of Appendices

Appendix 1: Ethical approval from SHSS Ethic Research Committee



Ref: NURSOS16

Ni Komang Ari Sawitri
Nursing Studies
School of Health in Social Science
Medical School
Teviot Place
Edinburgh
EH8 9AG

SCHOOL OF HEALTH IN SOCIAL SCIENCE
The University of Edinburgh
Doorway 6
Medical Quad
Teviot Place
Edinburgh
EH8 9AG

24 February 2016

E-mail: Susanne.Kean@ed.ac.uk Tel: 0131 651 1983
E-mail: Sarah.Rhynas@ed.ac.uk Tel: 0131 650 3882
Fax: 0131 650 3891

Dear Ari

APPLICATION FOR LEVEL 2/3 APPROVAL

PROJECT TITLE: FAMILIES' EXPERIENCES IN DAILY HYPERTENSION MANAGEMENT IN DEPASAR, BALI

Thank you for submitting the above research project for review by the Section of Nursing Studies Ethics Research Panel.

I can confirm that the submission has been independently reviewed and was approved on 23 February 2016.

Should there be any change to the research protocol, it is important that you alert us to this as this may necessitate further review.

Yours sincerely

Sarah J. Rhynas

Sarah J Rhynas
Teaching Fellow
Nursing Studies

Appendix 2: Ethic approval from The Ethic Committee of The Faculty of Medicine, Udayana University and Sanglah Hospital



UNIT PENELITIAN DAN PENGEMBANGAN
(LITBANG) FAKULTAS KEDOKTERAN
UNIVERSITAS UDAYANA/RUMAH SAKIT UMUM
PUSAT SANGLAH DENPASAR



Jalan P. Serangan Denpasar Bali (80114) Email : Litbang.unud.rsud@gmail.com Telp. (0361) 244534, (0361) 227911-15(p.227)

ETHICAL CLEARANCE

NO. 300/UN.14.2/Litbang/2016

This is to certify that following study project entitled :

"FAMILY'S EXPERIENCES IN DAILY HYPERTENSION MANAGEMENT IN DENPASAR, BALI."

Principal Investigator : Ns. Ni Komang Ari Sawitri, MSc.

Research Development: Puskesmas Wilayah Kota Denpasar

Protocol Number : 106.03.1.2016

Has been evaluated in accordance with the ethical aspects in using human being as a study subject and considered proper to be executed.

1. Progress report every..... month
2. Final report

Denpasar, 3/2/2016

Research and Development Unit,
Medical Faculty University of Udayana/
Sanglah Hospital Denpasar

dr. Ni Nengah Dwi Fatmawati, SpMK, Ph.D
NIP. 19780114 200212 2 003

Research Ethic Committee,
Medical Faculty University of Udayana /
Sanglah Hospital Denpasar

Prof. Dr. dr. Sri Maliawan, SpBS (K)
NIP. 19560114 198303 1 005

Appendix 3: Transcription symbols

() : Unclear section

(()) : An entry requiring comment but without a symbol to explain it

[] : Speech overlap

(h) : Laughter

Appendix 4: Information sheet for young children



Children's Information Sheets

Sometimes a(mum/ dad - substitute for family member relationship) can have an unhealthy condition and their heart works a bit too hard to pump the blood through their body and that is when the person's blood pressure can get too high. We call this Hypertension which is just another word for high blood pressure. There are some things a person with a high blood pressure can do to feel better. Eating a healthy diet, doing some regular exercise and sometimes taking some medication. In your family, your has a high blood pressure.

My name is Ari, and I am a nurse and a researcher, and I would like to talk to you about your having a family member that has high blood pressure. Before you decide if you want to talk to me about this, here is some information that I would like you to read first.

STUDY TITLE

Family's Experiences in Daily Hypertension Management in Denpasar City

WHAT IS THIS STUDY ABOUT?

I would like to ask you and your family questions about how it is to have a family member with high blood pressure.

WHY IS THIS STUDY BEING CARRIED OUT?

I am really interested in learning how a family can help a person with high blood pressure and keep them well and healthy and this information might then help people like me and other healthcare professionals helping people with high blood pressure and their families.

WHAT DO I HAVE TO DO?

If you decide to talk to me then I will come and visit you and your family. Sometimes I will just visit you and see what you and your family do to help your family member with high blood pressure feel better. But I also would like to talk to you and record our conversation (only with your permission). What you tell me will be kept between you and me and I will not use your or your family's name in any report I need to write.

DO I HAVE TO TAKE PART?

No - you do not have to take part in this study. You can say no and that is just fine. If you decide to take part, but change your mind later that will be O.K too. You just need to tell your parents or me.

FOR FURTHER INFORMATION

If you have any questions about all of this, please ask one of your parents to call me and we can have a chat. My number is: +62361243340

Thank you for thinking about my invitation!



Lembar Informasi dan Persetujuan untuk Anak- anak (Umur 8 – 10 tahun)

Bagaimana rasanya mempunyai saudara yang sedang sakit?

Nama saya Ari, saya ingin bertanya apakah kamu dan keluargamu mau menjadi peserta penelitian?

Tapi sebelum kamu menjawabnya, kamu perlu tahu tentang penelitian ini. Jadi, tolong dibaca kertas ini dengan baik bersama orang tuamu atau kita bisa membacanya bersama-sama.

Penelitian itu apa?

Penelitian adalah suatu cara untuk menjawab pertanyaan-pertanyaan yang penting.

Kadang-kadang, kakek atau nenek merasa kurang enak badan karena dia memiliki masalah dengan jantungnya. Kakek/nenek akan merasa lebih sehat bila dia meminum obatnya secara teratur, makan makanan yang bergizi, dan berolahraga secara teratur.

Penelitian ini dilakukan untuk mengetahui pengalaman keluargamu saat membantu nenek/kakek, menjadi lebih sehat. Pengalamanmu dan keluargamu sangat bermanfaat bagi dokter dan perawat, sehingga mereka dapat mengobati pasien yang punya masalah sama dengan kakek/nenekmu.

Apa yang harus saya lakukan?

Apabila kamu dan keluargamu setuju kalau kamu membantu saya dalam penelitian ini, maka nanti saya akan memberimu sebuah surat persetujuan. Lalu setelah itu saya akan datang ke rumahmu. Kamu dan keluargamu akan diwawancarai dan saya akan melihat bagaimana aktivitasmu di rumah. Saya punya alat perekam untuk merekam apa yang kita akan bicarakan, tapi kamu boleh meminta kepada saya untuk tidak merekam apa yang kita bicarakan. Saya tidak akan memberitahu siapapun kalau kamu membantu saya dalam penelitian ini.

Apakah saya harus ikut dalam penelitian ini?

Tidak, kamu tidak perlu ikut. Kamu bisa memilih untuk ikut ataupun tidak di dalam penelitian ini dan kamu juga bisa berhenti kapan saja, silahkan bilang kepada orang tuamu.

Apa yang harus saya lakukan kalau saya punya pertanyaan tentang penelitian ini? Kamu bisa bertanya kepada saya. Nama saya Ni Komang Ari Sawitri, nomer telepon saya : 081246896275. Kamu bisa minta tolong kepada orang tuamu untuk menelpon saya dan nanti saya akan menjawab pertanyaanmu.

Apabila kamu mau membantu saya dalam penelitian ini, tolong tulis namamu di bawah ini. Kamu juga akan mendapat lembaran yang sudah ditandatangani.

Apakah kamu bersedia untuk ikut serta dalam penelitian ini?

_____Ya, saya bersedia
bersedia

_____Tidak, saya tidak

Nama anak Tanda tangan

Tanggal

Nama peneliti Tanda tangan

Tanggal

Appendix 5: Information sheet for teenagers



University of Edinburgh School of Nursing

Teenager's Information Sheets

At times the health of a family member can be affected by a high blood pressure also called hypertension. Hypertension occurred when the heart works needs to work harder to pump blood through the body and this can, if untreated, lead to damages to the heart and other organs. The treatment of a person with high blood pressure includes a healthy diet, taking regular exercises and taking medication.

My name is Ari and I am a nurse and a researcher who is interested in studying family who live with a family member with high blood pressure. However, before you decide if you would like to take part in this study I would like you to read the information about my research.

STUDY TITLE

Family's Experiences in Daily Hypertension Management in Denpasar City

WHAT IS THIS STUDY ABOUT?

This study is about understanding how families live their lives when someone has a high blood pressure.

WHY IS THIS STUDY BEING CARRIED OUT?

I am interested in understanding what families do to support someone with a high blood pressure to keep them well and healthy, will help healthcare professionals to understand what we need to do to support families and patients with this condition.

WHAT DO I HAVE TO DO?

If you decide to take part then I would like to do two things: (1) come and visit your family and observe your life with someone with a high blood pressure – this really just means me being there and having a chat and (2) at a later point, interview you and ask you about your experiences of having a family member with a high blood pressure. I would like to record this interview only with your permission) so that I can later analyse the data. This is a normal procedure in research. What you tell me will be kept confidential between you and me. I will not identify your name in any reports or academic journal article. I will use a pseudonym so that neither you or your family can be identified. .

DO I HAVE TO TAKE PART?

No - you do not have to take part in this study. You can say no. This is entirely your choice. If you decide to take part, but later you change your mind that is fine too. Just tell me or if you prefer one of your parents.

FOR FURTHER INFORMATION

If you have any questions about all of this, you can call me at: +62361243340

Thank you for taking the time and considering my request!



**University of Edinburgh
School of Nursing**

Lembar Informasi Untuk Remaja

Terkadang salah satu anggota keluarga dapat mengalami tekanan darah tinggi atau disebut juga dengan hipertensi. Hipertensi terjadi saat jantung bekerja terlalu keras untuk memompa darah ke seluruh tubuh dan apabila tidak diobati dapat mengakibatkan kerusakan jantung dan organ tubuh lainnya. Pengobatan untuk hipertensi ini antara lain dengan makan makanan sehat, melakukan olah raga secara teratur dan mengkonsumsi obat secara teratur. Nama saya Ari dan saya seorang perawat dan peneliti yang tertarik untuk meneliti tentang keluarga yang merawat hipertensi. Akan tetapi sebelum kamu memutuskan untuk turut serta dalam penelitian ini, saya ingin agar kamu membaca terlebih dahulu informasi di bawah ini.

Judul penelitian

Pengalaman keluarga sehari-hari dalam mengontrol hipertensi di Denpasar, Bali
(Family's experiences in daily hypertension management in Denpasar, Bali)

Tentang apakah penelitian ini?

Penelitian ini akan mencari tahu bagaimana pengalaman keluarga dalam mengontrol tekanan darah tinggi dalam kehidupan sehari-hari.

Mengapa penelitian ini dilaksanakan?

Saya tertarik untuk memahami apa yang keluarga lakukan untuk menolong anggota keluarga yang mengalami tekanan darah tinggi agar tetap sehat. Informasi tersebut nantinya dapat membantu dokter dan perawat agar lebih paham saat membantu keluarga merawat pasien dengan tekanan darah tinggi.

Apa yang harus saya lakukan?

Apabila kamu bersedia untuk turut serta dalam penelitian ini maka saya akan :
(1) datang mengunjungi keluargamu dan mengobservasi kehidupanmu dan keluargamu – maksudnya adalah saya akan berada di rumahmu dan mengobrol
(2) lalu saya juga akan mewawancarai kamu dan keluargamu, lalu bertanya tentang pengalamanmu dengan anggota keluarga yang memiliki sakit tekanan darah tinggi. Saya akan merekam wawancara kita apabila kamu mengijinkannya, karena saya nanti akan mendengarkan pembicaraan kita kembali untuk kemudian saya analisa. Hal ini adalah prosedur normal dalam penelitian. Apapun yang nanti kamu sampaikan kepada saya akan terjaga kerahasiaanya. Namamu dan anggota keluarga yang lain akan diganti dengan nama samaran.

Apakah saya harus berpartisipasi?

Tidak – kamu tidak harus berpartisipasi dalam penelitian ini. Kamu bisa menolak. Ini adalah pilihanmu. Apabila kamu berpartisipasi, kemudian berubah pikiran, itu juga tidak menjadi masalah. Kamu hanya perlu menyampaikan kepada saya atau boleh juga disampaikan kepada orang tuamu.

Informasi lebih lanjut

Apabila kamu punya pertanyaan, bisa menghubungi saya di: 6281246896275 atau kirimkan email melalui: arisawitri.nk@gmail.com.

Terimakasih sudah meluangkan waktu dan mempertimbangkan permintaan saya.

Appendix 6: Information sheet for adult family members



University of Edinburgh School of Nursing Family Information Sheets

Dear family member,

Your family is being invited to take part in a research study. However, before you decide to take part in this study, it is very important to understand about the study, its aims and what it will involve. Therefore, please take time to read this information and discuss it with your family.

STUDY TITLE

Family's Experiences in Daily Hypertension Management in Denpasar City

WHAT IS THIS STUDY ABOUT?

This study will explore family's experiences in controlling high blood pressure at home in their daily life.

WHY IS THIS STUDY BEING CARRIED OUT?

This study aims to help health care providers gain more knowledge and a better understanding of family experience in controlling blood pressure in daily life. High blood pressure or hypertension is one of conditions if uncontrolled could lead into various chronic conditions include: stroke, cardiovascular diseases and kidney disease.

Family members in a household influence each other that may impact the health behaviour in controlling hypertension. However, to this date studies in blood pressure control have not explored all family members' involvement but merely focused on one or two members in a family. Therefore, for this current study all family members will be invited to take part, include children and young adults.

WHAT DO WE HAVE TO DO?

If your family decides to take part in this study and agree to sign the consent forms, the family will be interviewed and observed. The meetings will take place at your premises at a time that convenient for the family. The interview will be tape recorded and the observation will be noted (all with your permission). The recording will be used for research purposes only and then will be destroyed after completion of the study.

CONFIDENTIALITY

Any information that your family provides will be kept confidential between your family and the researcher. Any information about your family's identities (e g,

name, address, telephone number, email and occupation) will not be included in any forms of reports and presentations. Pseudonyms will be allocated to all participants.

DO WE HAVE TO TAKE PART?

No – you don't. Decision whether or not the family take part in this study entirely up to your family. If you decide to take part you can change your mind and withdraw your participation at any time without giving a reason. Your decision will not give any negative impact to you and your family.

ARE THERE ANY POSSIBLE ADVANTAGES IN TAKING PART?

There is no known benefits that directly can be obtained from this study, however, the information may be an important sources to improve hypertension management for health care providers.

ARE THERE ANY POSSIBLE DISADVANTAGES IN TAKING PART?

This study will not involve any invasive procedures or any other interventions and tests, therefore there are no known risks for the family in this study. However, if this study induces any psychological stress or discomfort, you will be referred to a GP.

WHO IS RESPONSIBLE FOR THIS STUDY?

This study is conducted as part of a Doctoral research project at the University of Edinburgh. The researcher (Ni Komang Ari Sawitri) is a qualified nurse and has experiences work with families. This study is supervised by Dr. Fiona Cuthill and Dr. Susanne Kean, of the University of Edinburgh.

HAS THIS STUDY BEEN REVIEWED?

Yes – this study has been reviewed and approved by Ethic Committee the University of Edinburgh and Research Ethic Committee Faculty Of Medicine Udayana University and Sanglah Hospital.

FOR FURTHER INFORMATION

If you have any questions about this study, you may contact the researcher (Ni Komang Ari Sawitri) at: +62361243340, or if you want to contact one of the supervisors (Dr. Fiona Cuthill or Dr. Susanne Kean, please contact the School of Nursing, University of Edinburgh, general enquiries at: +44 (0)131 651 3972



University of Edinburgh School of Nursing Lembar Informasi Untuk Keluarga

Yth. Seluruh anggota keluarga

Keluarga Anda diundang untuk berpartisipasi dalam sebuah penelitian. Akan tetapi sebelum memutuskan untuk turut serta dalam penelitian ini, sangat penting bagi Anda sekeluarga untuk memahami tentang penelitian ini, tujuannya dan segala sesuatu yang terkait dengan penelitian ini. Sehingga kami mohon Anda sekeluarga meluangkan waktu untuk membaca informasi di bawah ini dan mendiskusikannya terlebih dahulu dengan seluruh anggota keluarga.

Judul penelitian

Pengalaman keluarga sehari-hari dalam mengontrol hipertensi di Denpasar, Bali
(Family's experiences in daily hypertension management in Denpasar, Bali)

Tentang apakah penelitian ini?

Penelitian ini akan mencari tahu bagaimana pengalaman keluarga dalam mengontrol tekanan darah tinggi dalam kehidupan sehari-hari.

Mengapa penelitian ini dilaksanakan?

Penelitian ini bertujuan untuk membantu tenaga kesehatan dalam memperoleh ilmu pengetahuan dan lebih memahami pengalaman sehari-hari keluarga dalam mengontrol tekanan darah. Hipertensi atau tekanan darah tinggi adalah suatu kondisi yang apabila tidak terkontrol akan mengakibatkan berbagai kondisi kronik lainnya seperti: stroke, penyakit jantung dan penyakit ginjal.

Anggota keluarga bias saling mempengaruhi satu sama lain yang akan berdampak pada perilaku kesehatan dalam mengontrol tekanan darah. Akan tetapi sehingga saat ini penelitian-penelitian sejenis belum mempelajari bagaimana keterlibatan seluruh anggota keluarga dalam mengontrol tekanan darah, namun hanya berfokus pada salah satu anggota keluarga saja. Sehingga, untuk penelitian ini seluruh anggota keluarga akan dilibatkan termasuk anak-anak dan remaja.

Apa yang harus dilakukan oleh keluarga

Jika keluarga memutuskan untuk berpartisipasi dalam penelitian ini dan menandatangani lembar persetujuan, maka keluarga akan dilakukan wawancara dan pemantauan (observasi) kegiatan sehari-hari. Wawancara dan pemantauan akan dilaksanakan di kediaman keluarga di waktu yang disepakati oleh keluarga. Wawancara akan direkam dan observasi akan dicatat (semua dilakukan atas persetujuan seluruh anggota keluarga). Hasil wawancara dan observasi hanya akan digunakan untuk kepentingan penelitian dan semua data akan dihancurkan setelah penelitian selesai.

Kerahasiaan

Seluruh informasi yang disampaikan oleh anggota keluarga akan dijaga kerahasiaannya dan hanya diketahui oleh keluarga dan peneliti. Seluruh informasi yang mengandung data pribadi anggota keluarga (seperti misalnya: nama, alamat, nomor telepon, alamat e-mail dan pekerjaan) tidak akan dimunculkan dalam laporan penelitian ataupun dalam presentasi. Seluruh nama akan diganti dengan nama samaran.

Apakah keluarga harus berpartisipasi?,

Tidak – Anda tidak harus berpartisipasi. Keputusan apakah keluarga akan turut serta atau tidak, seluruhnya menjadi hak keluarga. Keluarga juga berhak untuk mengundurkan diri tanpa alasan. Keputusan yang diambil tidak akan memberi dampak negatif pada Anda dan keluarga Anda.

Apakah ada keuntungan bila berpartisipasi dalam penelitian ini?

Penelitian ini tidak memberikan keuntungan secara langsung, akan tetapi hasil dari penelitian ini merupakan informasi yang sangat berharga bagi tenaga kesehatan untuk perawatan dan pengobatan hipertensi.

Apakah kerugian bila terlibat dalam penelitian ini?

Tidak ada tindakan medis ataupun tes lainnya dalam penelitian ini, sehingga tidak membahayakan anggota keluarga. Akan tetapi bila penelitian menimbulkan stress atau gangguan psikologis lainnya, Anda akan dirujuk ke dokter.

Siapakah yang bertanggung jawab untuk penelitian ini?

Penelitian ini dilaksanakan sebagai bagian dari proyek penelitian S3 di Universitas Edinburgh. Peneliti utama adalah Ni Komang Ari Sawitri, seorang perawat dan memiliki pengalaman merawat keluarga. Dosen pembimbing untuk proyek penelitian ini adalah Dr. Fiona Cuthill dan Dr. Susanne Kean, dari Universitas Edinburgh.

Apakah penelitian ini sudah layak untuk dilakukan?

Ya- penelitian ini telah diuji dan disetujui oleh Komite Etik di Universitas Edinburgh dan Komite Etik Penelitian Fakultas Kedokteran UNUD dan RSUP Sanglah.

Informasi lebih lanjut

Bila Anda memiliki pertanyaan tentang penelitian ini silahkan untuk menghubungi peneliti (Ni Komang Ari Sawitri) di nomor: 0361243340, atau jika Anda ingin menghubungi salah satu pembimbing (Dr Fiona Cuthill atau Dr. Susanne Kean), silahkan untuk menghubungi School of Nursing, University of Edinburgh, di nomor: +44 (0)131 651 3972.

Appendix 7: Invitation letter



Letter of Invitation

Date

Name

Address

Dear (name),

My name is Ni Komang Ari Sawitri, a PhD student from The University of Edinburgh, Scotland. I am conducting a study as part of requirements of my degree in Nursing Studies, and I would like to invite you and your family to participate.

I am very interested in studying blood pressure control in daily life. This current study aims to explore family's experiences in controlling high blood pressure in daily life. If you and your family decide to participate, you and your family will be interviewed about daily experiences in controlling blood pressure. In addition, your and your family's daily activities will be observed. The meeting will take place at your premises at mutually agreed upon time. The interview will be tape recorded and the observation will be noted. However, if you and your family may feel uncomfortable answering some questions or being observed, you do not have to answer and you can refused for being observed. The recording and notes will only be used for this study purposes and then will be destroyed. The results of this study may be published in journals or conferences but, no one will know your answers because all identities will not be revealed.

The results of this study will not directly affect you and your family, but I hope that the results of this study could help the health care provider in providing suitable care for hypertension patients.

You and your family do not have to participate in this study. You also can withdraw your participation any time without giving a reason. Your decision will not give you and your family any negative impact.

If you and your family are interested to take part in this study, please contact me at : +62361243340 to discuss participating. I will wait for your confirmation until(date/month/year). I will be happy to answer any questions you have about this study.

Thank you.

Sincerely,
Ni Komang Ari Sawitri



Surat Undangan Untuk Berpartisipasi Dalam Penelitian

Tanggal

Nama :

Alamat :

Yth

Nama saya Ni Komang Ari Sawitri, seorang staf pengajar di Program Studi Ilmu Keperawatan FK UNUD, saat ini saya sedang menempuh pendidikan S3 di Universitas Edinburgh, Skotlandia. Saya sedang melakukan penelitian sebagai bagian dari syarat pendidikan S3 Ilmu Keperawatan yang sedang saya jalani. Melalui surat ini saya ingin mengundang Anda dan keluarga Anda untuk berpartisipasi dalam penelitian saya yang berjudul **“Pengalaman sehari-hari keluarga dalam mengontrol Hipertensi di Denpasar, Bali”**

Saya sangat tertarik untuk melakukan penelitian tentang pengontrolan tekanan darah dalam kehidupan sehari-hari. Penelitian ini bertujuan untuk memahami bagaimana pengalaman keluarga dalam mengontrol tekanan darah sehari-hari di rumah. Apabila Anda sekeluarga memutuskan untuk berpartisipasi dalam penelitian ini, maka Anda sekeluarga akan diwawancara mengenai pengalaman sehari-hari dalam merawat anggota keluarga dengan tekanan darah tinggi. Selain itu, saya juga akan mengobservasi kegiatan sehari-hari keluarga di rumah. Setiap pertemuan akan dilaksanakan di rumah Anda sekeluarga dengan waktu sesuai kesepakatan. Setiap wawancara akan saya rekam dan observasi akan saya catat. Apabila Anda dan keluarga merasa tidak nyaman dengan pertanyaan yang saya ajukan ataupun keberatan untuk diobservasi, Anda sekeluarga memiliki hak untuk menolak. Rekaman wawancara dan catatan observasi hanya akan digunakan untuk keperluan penelitian saja dan akan dihancurkan apabila sudah tidak dipergunakan lagi. Hasil dari penelitian ini mungkin akan dimuat di jurnal ataupun disampaikan dalam konferensi, tapi tidak akan ada yang tahu apa jawaban Anda saat wawancara karena semua identitas akan disamarkan.

Hasil dari penelitian ini tidak akan memberi dampak langsung pada Anda dan keluarga Anda, tetapi saya berharap hasil dari penelitian ini dapat membantu tenaga kesehatan untuk menyediakan perawatan yang sesuai untuk pasien-pasien dengan tekanan darah tinggi.

Anda dan keluarga Anda tidak harus berpartisipasi dalam penelitian ini. Anda sekeluarga juga dapat membatalkan keikutsertaan dalam penelitian ini tanpa harus memberi alasan. Keputusan Anda sekeluarga tidak berdampak negative pada Anda dan keluarga Anda.

Apabila Anda dan keluarga tertarik untuk ikut serta dalam penelitian ini, mohon untuk menghubungi saya (Ni Komang Ari Sawitri) di nomer hp: **081246896275** atau di nomor telepon: **0361243340** untuk berdiskusi. Saya akan menunggu konfirmasi dari Anda seminggu setelah Anda menerima surat undangan ini. Saya akan sangat senang menjawab setiap pertanyaan yang Anda ajukan mengenai penelitian ini.

Terimakasih,

Salam

Ni Komang Ari Sawitri

Appendix 8: Consent form for young children



University of Edinburgh School of Nursing

Children's Consent Form

STUDY TITLE

Family's Experiences in Daily Hypertension Management in Denpasar City

I,.....(printed name), agree to take part in the study conducted by Ni Komang Ari Sawitri (PhD Student).

I confirm that (please tick box as appropriate):

- | | | |
|---|--|--|
| 1 | I have read and understood the information about the study | |
| 2 | I would like to take part in Ari's study. | |
| 3 | It was my decision to take part in Ari's study. | |
| 4 | I understand that Ari will asked me some questions and that she also will come and see how I and my family live. | |
| 5 | I understand the Ari will record our interview. | |
| 6 | I understand that I do not need to take part and that I can change my mind anytime. | |
| 7 | I know that I can ask Ari any questions about this study to Ni Komang Ari Sawitri at +62361243340 | |

Participant _____

Researcher _____

Date _____



**University of Edinburgh
School of Nursing**

Lembar Persetujuan Anak

Judul penelitian

Pengalaman keluarga sehari-hari dalam mengontrol hipertensi di Denpasar, Bali
Saya,(nama), setuju untuk berpartisipasi dalam penelitian yang
dilakukan oleh Ni Komang Ari Sawitri (Mahasiswa S3).

Saya menyatakan bahwa (berilah tanda centang pada kotak yang tersedia):

- 1 Saya sudah membaca dan paham tentang penelitian Ari ☐
- 2 Saya ingin turut serta dalam penelitian Ari ☐
- 3 Saya yang ingin dalam penelitian Ari ☐
- 4 Saya tahu Ari akan bertanya dan melihat keluarga saya ☐
- 5 Saya tahu Ari akan merekam apa yang saya bilang ☐
- 6 Saya tahu saya boleh berhenti dan tidak ikut dalam penelitian Ari ☐
- 7 Saya tahu kalau saya bisa bertanya kepada Ari di nomer : ☐
6281246896275

Partisipan _____

Peneliti _____

Tanggal _____

Appendix 9: Consent form for teenagers



**University of Edinburgh
School of Nursing**

Teenager's Consent Sheets

STUDY TITLE

Family's Experiences in Daily Hypertension Management in Denpasar

I,.....(printed name), agree to participate in the study conducted by Ni Komang Ari Sawitri (PhD Student).

I confirm that (please tick box as appropriate):

- | | | |
|---|--|--------------------------|
| 1 | I have read and understood the information about the study | <input type="checkbox"/> |
| 2 | It is my decision to take part in the study. | <input type="checkbox"/> |
| 3 | I understand that I will be asked questions and Ari will observe our daily family life. | <input type="checkbox"/> |
| 4 | I understand the conversation will be recorded and will be kept confidential. | <input type="checkbox"/> |
| 5 | I understand that my real name will not be revealed in this study | <input type="checkbox"/> |
| 6 | I understand that I do not have to take part in this study and that I can change my mind at any time. | <input type="checkbox"/> |
| 7 | I know that I can ask Ari any questions I may have about this study to Ni Komang Ari Sawitri at +62361243340 | <input type="checkbox"/> |

Participant _____

Researcher _____

Date _____



**University of Edinburgh
School of Nursing**

**Lembar Persetujuan
(Remaja)**

Judul penelitian

Pengalaman keluarga sehari-hari dalam mengontrol hipertensi di Denpasar, Bali
Saya,(nama), setuju untuk berpartisipasi dalam penelitian yang
dilakukan oleh Ni Komang Ari Sawitri (Mahasiswi S3).

Saya menyatakan bahwa (berilah tanda centang pada kotak yang tersedia):

- 1 Ari sudah menjelaskan tentang penelitian ini kepada saya dan saya ☐
paham tentang itu
- 2 Saya yang memutuskan untuk turut serta dalam penelitian Ari ☐
- 3 Saya mengerti bahwa nanti Ari akan mewawancara dan ☐
mengobservasi kehidupan sehari-hari keluarga saya.
- 4 Saya mengerti bahwa nanti wawancara saya dengan Ari akan ☐
direkam
- 5 Saya mengerti bahwa saya tidak harus ikut dalam penelitian ini dan ☐
saya bisa berubah pikiran kapan saja.
- 6 Saya mengerti kalau hasil wawancara dan observasi akan ☐
digunakan dalam laporan, tapi Ari tidak akan menuliskan nama asli
saya di dalamnya.
- 7 Saya tahu kalau saya bisa bertanya kepada Ari di nomer : ☐
6281246896275 atau kirimkan e-mail ke: arisawitri.nk@gmail.com

Partisipan _____

Peneliti _____

Tanggal _____

Appendix 10: Consent form for adult family members



University of Edinburgh
School of Nursing
Adult Family Member's Consent Form

PROJECT TITLE

Family's Experiences in Daily Hypertension Management in Denpasar

This is to certify that I, (printed name), hereby consent to participate in the study conducted by Ni Komang Ari Sawitri (PhD Student).

I confirm that (please tick box as appropriate):

- | | | |
|---|--|--------------------------|
| 1 | I have read and understood the information about the project, as provided in the information sheet dated | <input type="checkbox"/> |
| 2 | I voluntarily agree to participate in the project | <input type="checkbox"/> |
| 3 | I understand that I will be interviewed and observed | <input type="checkbox"/> |
| 4 | I understand that all interviews will be tape recorded and the observations will be noted | <input type="checkbox"/> |
| 5 | I understand that I have the right to withdraw my participation any time without a reason, refuse to answer questions and being observed | <input type="checkbox"/> |
| 6 | I understand that the study will not give direct benefit nor negative impact to me and my family | <input type="checkbox"/> |
| 7 | The procedures regarding confidentiality have been clearly explained that pseudonyms will be allocated to all participants | <input type="checkbox"/> |
| 8 | The use of data has been explained to me | <input type="checkbox"/> |
| 9 | I have been given the opportunity to ask questions about this study to Ni Komang Ari Sawitri at +62361243340 or arisawitri.nk@gmail.com | <input type="checkbox"/> |

Participant _____

Researcher _____

Date _____



University of Edinburgh

School of Nursing

Lembar Persetujuan Partisipan Penelitian

(Dewasa)

Judul Penelitian

Pengalaman Sehari-hari Keluarga dalam Mengontrol Hipertensi di Denpasar Bali

Dengan ini, saya(nama) menyatakan bahwa setuju untuk berpartisipasi dalam penelitian yang dilaksanakan oleh Ni Komang Ari Sawitri (mahasiswi PhD).

Saya nyatakan bahwa (beri tanda centang pada kotak yang tersedia) :

- 1 Saya telah membaca dan memahami informasi tentang penelitian yang akan dilaksanakan, sesuai dengan apa yang tertulis di dalam lembar informasi, pada tanggal ☐
- 2 Saya secara suka rela ikut berpartisipasi dalam penelitian ini ☐
- 3 Saya paham bahwa saya akan diwawancara dan diamati (diobservasi) ☐
- 4 Saya paham bahwa akan dilakukan perekaman saat wawancara dan pencatatan saat observasi ☐
- 5 Saya paham bahwa saya memiliki hak untuk mengundurkan diri dari penelitian kapan saja tanpa alasan sekalipun , menolak menjawab pertanyaan dan menolak untuk diobservasi ☐
- 6 Saya mengerti bahwa penelitian ini tidak akan memberi dampak secara langsung kepada saya dan keluarga saya ☐
- 7 Prosedur tentang kerahasiaan telah dijelaskan secara gamblang yaitu semua nama akan diganti dengan nama samaran ☐
- 8 Penggunaan hasil wawancara dan observasi telah disampaikan dengan jelas ☐
- 9 Saya telah diberikan kesempatan untuk bertanya terkait penelitian ini kepada Ni Komang Ari Sawitri dengan nomer telepon +62361243340 atau alamat e-mail: arisawitri.nk@gmail.com ☐

Partisipan _____

Peneliti _____

Tanggal _____

Appendix 11: Consent form for parents



University of Edinburgh
School of Nursing
Parental Consent Form

PROJECT TITLE

Family's Experiences in Daily Hypertension Management in Denpasar

This is to certify that I, the parent, hereby consent to the participation of our child, (name printed) in the study conducted by Ni Komang Ari Sawitri (PhD Student).

I confirm that (please tick box as appropriate):

- | | | |
|----|---|--------------------------|
| 1 | I have read and understood the information about the project, as provided in the information sheet dated | <input type="checkbox"/> |
| 2 | I agree that my child can be approached for participation in the study. | <input type="checkbox"/> |
| 3 | I understand that it is my child's decision to participate. | <input type="checkbox"/> |
| 4 | I understand that my child(ren) will be interviewed and observed | <input type="checkbox"/> |
| 5 | I understand that all interviews will be recorded and the observational notes will be taken | <input type="checkbox"/> |
| 6 | I understand that I have the right to withdraw my children's participation at any time without giving a reason or refuse to answer questions and being observed | <input type="checkbox"/> |
| 7 | I understand that the study will not have a direct benefit nor negative impact to my family | <input type="checkbox"/> |
| 8 | The procedures regarding anonymity and confidentiality have been clearly explained and that pseudonyms will be used for all participants | <input type="checkbox"/> |
| 9 | The use of data has been explained to me | <input type="checkbox"/> |
| 10 | We have been given the opportunity to ask questions about this study to Ni Komang Ari Sawitri at +62361243340 or arisawitri.nk@gmail.com | <input type="checkbox"/> |

Parents _____

Researcher _____

Date _____



University of Edinburgh
School of Nursing
Persetujuan Orang Tua

Judul Penelitian

Pengalaman Keluarga Sehari-hari dalam Mengontrol Hipertensi di Denpasar Bali

Dengan ini saya menyatakan bahwa saya sebagai orang tua, dengan ini menyatakan setuju atas keikutsertaan anak kami(nama) dalam penelitian yang dilaksanakan oleh Ni Komang Ari Sawitri (Mahasiswi S3)

Saya menyatakan (silahkan beri centang pada kotak yang telah disesuaikan) :

- 1 Saya telah membaca dan memahami informasi tentang penelitian ini, sesuai dengan lembar informasi yang telah disediakan ☐
- 2 Saya setuju bahwa anak-anak kami dapat diajak untuk menjadi partisipan penelitian ☐
- 3 Saya paham bahwa anak saya dapat menentukan apakah mereka bersedia untuk menjadi partisipan atau tidak
- 4 Saya paham bahwa anak-anak saya akan diwawancara dan diobservasi ☐
- 5 Saya mengerti bahwa proses wawancara akan direkam dan setiap observasi akan dicatat ☐
- 6 Saya paham bahwa saya punya hak untuk membatalkan keikutsertaan anak-anak saya kapan saja tanpa perlu memberi alasan atau menolak memberi jawaban dan diobservasi ☐
- 7 Saya paham bahwa penelitian ini tidak memberikan keuntungan secara langsung kepada keluarga saya. ☐
- 8 Penataksanaan terkait penggunaan nama samaran dan kerahasiaan sudah disampaikan dengan sangat jelas. Nama samaran akan digunakan pada seluruh partisipan ☐
- 9 Penggunaan hasil wawancara dan observasi sudah dijelaskan ☐
- 10 Kami sudah diberikan kesempatan untuk bertanya tentang penelitian ini kepada Ni Komang Ari Sawitri di nomer +62361243340 atau arisawitri.nk@gmail.com ☐

Orang tua _____
Peneliti _____
Tanggal _____

Appendix 12: Consent form for the head of famil



University of Edinburgh
School of Nursing
The Head of Family Consent Form

PROJECT TITLE

Family's Experiences in Daily Hypertension Management in Denpasar

This is to certify that I, (printed name), the head of family, hereby consent to participate in the study conducted by Ni Komang Ari Sawitri (PhD Student).

I confirm that (please tick box as appropriate):

- | | | |
|---|---|--------------------------|
| 1 | I have read and understood the information about the project, as provided in the information sheet dated | <input type="checkbox"/> |
| 2 | I voluntarily agree that my family to participate in the project | <input type="checkbox"/> |
| 3 | I understand that our family will be interviewed and observed | <input type="checkbox"/> |
| 4 | I understand that during the study in our premises, all interviews will be tape recorded and the observations will be noted | <input type="checkbox"/> |
| 5 | I understand that I have the right to withdraw my family's participation any time without a reason, refuse to answer questions and being observed | <input type="checkbox"/> |
| 6 | I understand that the study will not give direct benefit nor negative impact to my family | <input type="checkbox"/> |
| 7 | The procedures regarding confidentiality have been clearly explained that pseudonyms will be allocated to all participants | <input type="checkbox"/> |
| 8 | The use of data has been explained to us | <input type="checkbox"/> |
| 9 | We have been given the opportunity to ask questions about this study to Ni Komang Ari Sawitri at +62361243340 or arisawitri.nk@gmail.com | <input type="checkbox"/> |

Head of the family _____

Researcher _____

Date _____



University of Edinburgh
School of Nursing
Persetujuan Kepala Keluarga

Judul Penelitian

**Pengalaman Keluarga Sehari-hari dalam Mengontrol Hipertensi di
Denpasar Bali**

Dengan ini saya menyatakan bahwa Saya, sebagai kepala keluarga
dengan ini menyatakan setuju untuk ikut serta dalam penelitian yang dilaksanakan
oleh Ni Komang Ari Sawitri (Mahasiswi S3)

Saya menyatakan (silahkan beri centang pada kotak yang telah disesuaikan) :

- | | | |
|---|---|--|
| 1 | Saya telah membaca dan memahami informasi tentang penelitian ini, sesuai dengan lembar informasi yang telah disediakan | |
| 2 | Saya secara sukarela setuju keluarga saya berpartisipasi dalam penelitian ini | |
| 3 | Saya paham bahwa keluarga kami akan diinterview dan diobservasi | |
| 4 | Saya paham bahwa selama penelitian di rumah kami, percakapan selama wawancara akan dilakukan perekaman dan pencatatan selama observasi. | |
| 5 | Saya paham bahwa saya memiliki hak untuk membatalkan keikutsertaan keluarga saya kapan saja tanpa perlu memberi alasan atau menolak memberi jawaban dan diobservasi | |
| 6 | Saya paham bahwa penelitian ini tidak memberikan keuntungan secara langsung kepada keluarga saya | |
| 7 | Penatalaksanaan terkait penggunaan nama samaran dan kerahasiaan sudah disampaikan dengan sangat jelas. Nama samaran akan digunakan pada seluruh partisipan | |
| 8 | Penggunaan hasil wawancara dan observasi sudah dijelaskan | |
| 9 | Kami sudah diberikan kesempatan untuk bertanya tentang penelitian ini kepada Ni Komang Ari Sawitri di nomer +62361243340 atau arisawitri.nk@gmail.com | |

Kepala keluarga _____

Peneliti _____

Tanggal _____

Appendix 13: Interview guideline

INTERVIEW GUIDELINE

X = the family member with hypertension

A. Family's perception of hypertension

1. Can you tell me about hypertension?
2. Please describe the causes of hypertension?
3. Could you describe the treatment for hypertension?

Probing question:

What could happen if it is untreated?

B. Family's involvement in hypertension management

1. Do you remember when X was first diagnosed with hypertension?

Specific questions:

What were the signs and symptoms that X had at that time?

How the family found out about the hypertension?

Probing questions:

How was the family situation at that time?

How was the family's reaction when X was diagnosed with hypertension?

What had been done at that time?

2. Can you tell me X's condition so far?

Probing questions:

How's the family reactions and feelings to X condition so far?

Whether the hypertension affects family's daily life? Please explain

Has X ever had emergency condition because of his/her increasing blood pressure? Please explain

What was family reaction to the emergency situation?

Do you think it is important to keep X's blood pressure in normal range? Why?

3. What do you think should be done for X to keep healthy?

4. What have been done so far in order to maintain X's health?

Specific questions:

Why those are chosen to be done?

How the implementation?

Who has done it?

Where those are done

When ?

5. What do you think about the activities (in number 4)?

Probing question:

Is there any other procedure that should have been done in addition to the answers in number 4?

C. Barriers and facilitators of hypertension management

1. Could you please explain to me in detail how the procedures in number 4 have been done?

Probing questions:

Whether all could have been done in daily life? Please explain

Have the family ever find obstacles in conducting those procedures?

Please explain

What have been done to ease the problems?

What situations could help the implementation of those procedures?

Please explain

2. How can health services provide help for patients with hypertension?

3. What is family's expectation of hypertension treatment?

4. Is there anything else that family want to tell me in respect of hypertension management?

Appendix 14: Observation guideline

Six categories of FFAM guide the observations:

1. Identifying data :

- a. family name
- b. their address and phone number,
- c. family composition (genogram)
- d. type of family form
- e. cultural background
- f. religious identification

2. Developmental stage and history of family

The family's development in its attempts at controlling its member's hypertension. Families' experiences of controlling hypertension from the beginning, their current experiences and future challenges have been presented in this section.

3. Environmental data

The families' and patients' awareness of public amenities and services that facilitate hypertension control, and whether the facilities are adequate for the families to support their hypertension control efforts, are also evident in this section.

4. Family structure

The way family members related to each other, in terms of their hypertension control practices, by focusing on who has the power in the family for making decisions regarding hypertension control-related activities.

5. Family functions

The families' knowledge and perception regarding the issue of hypertension, the roles of the family in daily hypertension control and the family's awareness toward hypertension are presented in a reflective way.

6. Family stress, coping and adaptation.

Emotional expression, and its impact on family response strategies.

Appendix 15: analytic memo

Grand parenting

Taking care of the grandchildren is a prominent daily activity for the patient. But when I compared these two interview excerpts I think grand parenting have positive and negative influence in hypertension control. Pak Hendra, has two grandsons and his wife said the grandsons are the cause of stress because they are stubborn.

Because, well sometimes, (the anger) never come out, it just, to be honest, sometimes my grandsons. (Pak Hendra)

They are stubborn. (Bu Maya)

Because of their stubbornness. (Pak Hendra)

Moreover when the three of them at home, they (grandsons) perhaps being stubborn, maybe tired, he's tired, he thinks too much, sometimes his blood pressure increases, but it's not too dangerous, I think. (Bu Maya)

I intrigued with grand parenting activities. Another patient Bu Lely also complained similar matter. Bu Lely mentioned that her grandchildren sometimes caused stress. She opened up about this matter when I asked if she ever feel stress. She then mentioned that at some point her grandchildren is the source of her stress. She said if she is getting older she could not chase them when they go too far away from home. When she could not find them she would start to worry about their safety, and this caused the stress.

On the other hand, Pak Kanda and his wife said if actually his grand daughter has helped him to do more exercise. This because almost everyday he

The good thing is she willing to walk, and later on she would say "piggyback please?" then (we) go home on piggyback. (Pak Kanda)

Is it part of your exercise? (AS)

[Yes, because the walks, her walks] (Pak Kanda)

[She goes everywhere, piggyback] (Bu Dinda)

The walk was vigorous, it's not a lazy walk (Pak Kanda)

Where do you go? Is it far? (AS)

Around here, (we) circle this (his pointing finger made invisible circle for his neighbourhood) (Pak Kanda)

Visiting our neighbours, (h) exploring (h) (Jepun)

She doesn't walk, she runs, that's why we also run, she runs fast. That's why the doctor said walk is good, but not lazy walk, it has to have (vigorous) movements, to train the muscles (Pak Kanda)

Other patients who were also grand parents such as Pak Wimar, he has 2 grandsons, never revealed if taking care the grandchildren as a burden that causes stress. Instead he enjoyed spending the time with them.

Taking care of the grandchildren should be related to the roles and responsibilities in the family (System theory). The patients took part in taking care their grandchildren because the parents have to work, so the grandparents should step in take the responsibilities while the parents at work.

The stress can be caused by the grandchildren behaviour. Such as what Pak Hendra and his wife said about their grandsons. The children behaviour change depend on their age and stage of development (children development). The grandchildren above aged 2-4 years old. If I compared to Pak Kanda's older grandchildren aged >10 years old, they did not need to be taken care by the grandparents, so the older grandchildren may not give much stress. But Pak Kanda's grand daughter was 2 years old, even though Pak Kanda said taking care of her helped him to do exercise but she might at some point annoys Pak Kanda. As an aunty I had experiences taking care my niece and nephew, and they can be so annoying sometimes.

Other than the grandchildren behaviour, another situation probably because whether the patient share their responsibilities with their spouse or other family members. In Pak Kanda's family, there is Bu Dinda, who also taking care of the grand daughter. Meanwhile Pak Hendra has two grandsons, but he mostly the one who took care of them, because the other family members still have to work. Pak Kanda's family also consists of more family members than Pak Hendra, therefore with more people the responsibilities can be shared.

The above excerpts showed different views regarding taking care the grandchildren. But that maybe not differences but that's the nature of taking care of the grandchildren. Sometime children can be so annoying and create difficulties for the parents and grandparents. But in other time they amuse their grandparents. I remember when my parents sometimes complaining my niece and nephew

behaviour, but the other time the children amuse my parents. Therefore, the impact of grand parenting activity will change over time never static.